CHILDREN'S HEALTH: BUILDING TOWARD A BETTER FUTURE

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CONTENTS

Page

Testimony of:
Kattan, Meyer, Department of Pediatrics, Mt. Sinai Hospital 35
Mahr, Wesley, accompanied by Mackenzie Mahr, on behalf of Juvenile Diabetes Foundation International 27
Pierce, William, National Council for Adoption 29
Russo, Rene, Board Member, Cure Autism Now, accompanied by Jonathon Shestack, President, Cure Autism Now 10
Weisman, Richard S., Department of Pediatrics, University of Miami School of Medicine, on behalf of American Association of Poison Control Centers 39
Young, Francine 13

CHILDREN'S HEALTH: BUILDING TOWARD A BETTER FUTURE

TUESDAY, OCTOBER 12, 1999

HOUSE OF REPRESENTATIVES,
COMMITTEE ON COMMERCE,
SUBCOMMITTEE ON HEALTH AND ENVIRONMENT,
Washington, DC.

The subcommittee met, pursuant to notice, at 3:40 p.m., in room 2123, Rayburn House Office Building, Hon. Michael Bilirakis (chairman) presiding.

Members present: Representatives Bilirakis, Greenwood, Ganske, Brown, Waxman, Stupak, Strickland, DeGette, and Towns.

Staff present: Jason Lee, majority counsel; Marc Wheat, majority counsel; Kristi Gillis, legislative clerk; and John Ford, minority counsel.

Mr. BILIRAKIS. I call to order this hearing on Children's Health: Building Toward a Better Future. Before I go into the chairman's opening statement, we just held a press conference out in the triangle in front of the Capitol; and it was just gang busters. It was just wonderful; led, of course, by Ms. Russo. There was a lot of demonstrating there and everything for the cameras which is really just wonderful. It is democracy in action. The only problem is the House rules. The rules of the House prohibit the use of signs and placards and whatnot on the floor as well in the hearing room.

So please we are all together on this. We all want to succeed as well as we possibly can, but I would ask you in a very nice way to try to keep down your enthusiasm. The applause and that sort of thing from the audience, if you have ever been in the House chambers up in the gallery, it is not allowed and not allowed here. We sometimes will applaud the witnesses, but it is not a good idea for the witnesses to applaud us. So in any case, I ask your cooperation.

Mr. BROWN. Mr. Chairman, normally they don't want to.

Mr. BILIRAKIS. I guess I don't blame them. As a father and grandfather, I know that our children are America's future. It is appropriate, therefore, that we place a great deal of emphasis on their health and well being.

Today we will examine some of the difficult barriers that we face in working to improve children's health. I want to thank all of our witnesses for taking the time to share their knowledge and personal experiences with us. Before we begin, we should consider how far we have come as a Nation. A baby born in American today has a life expectancy 30 years longer than a child born at the turn of

the century. Public health initiatives are largely responsible for this vast, vast improvement.

But we cannot, we must not rest on our laurels because much more remains to be done. Today we will learn about some deeply troubling trends in the rates of certain childhood afflictions. We will also learn what Congress can do to help.

First, we will discuss the increasing prevalence of autism, which is now the third most common developmental disorder affecting America's children. For many years, autism was tragically misdiagnosed as an emotional disorder. Today, however, scientists hope that new medical treatments and a cure can be identified.

We will also examine the nearly epidemic proportion of children, almost 5 million nationwide, who suffer from childhood asthma. In addition, we will focus on the debilitating effects of juvenile diabetes which affects hundreds of thousands of American children in every State. Sadly despite its name, this disease, as you know, is never outgrown.

Today we will also discuss measures to promote adoption of children with special health needs. Although the rate of infant deaths due to birth defects has been cut in half since 1960, birth defects remain the leading cause of infant mortality and a major cause of disability in young children. I share the heartfelt desire of the full committee chairman, Tom Bliley, and many of the members of this subcommittee to encourage the adoption of these special children.

Finally, we will also focus on one of the most effective means currently available for reducing childhood deaths, namely poison prevention and control. About 60 percent of poisonings each year involve children less than 6 years old. I look forward to hearing about how we can help prevent the millions of poisonings that occur annually.

Childhood diseases afflict pain and disruption on countless American children and their families. Certainly their human toll cannot be calculated. However, they also take a financial toll through billions of dollars in increased health care cost. From a financial perspective, therefore, every dollar spent by the Federal Government on disease research and prevention is an extremely wise investment. For the patients' families, caregivers, and friends whose lives have been touched by childhood diseases, we should renew and strengthen our commitment to finding the causes of and cures for these terrible afflictions.

I want to again express my sincere gratitude to all of the witnesses who will appear before us and in particular, of course, I want to extend a special welcome to Ms. Russo, Ms. Rene Russo, who has taken time from her very, very busy schedule to speak about a topic that I know matters a great deal to her personally.

I would also like to acknowledge the efforts of several members of this subcommittee who have worked to develop individual bills addressing many of the topics before us today. I look forward to working together with you and the ranking member, Mr. Brown, to develop a comprehensive children's health measure that can be enacted with bipartisan support. At this time I yield to my good friend from Ohio, the ranking member of this subcommittee, Mr. Brown.

Mr. BROWN. Mr. Chairman, thank you. Welcome to Ms. Young and Ms. Russo and our other distinguished witnesses. Thank you for joining us. Today's hearing calls attention to a wide range of children's issues, each of them critically important in its own right.

Our first panel will focus on autism, an alarmingly prevalent disorder about which far too little is known. The children of autism relate to their world in a way that we don't fully understand and cannot fully penetrate. What we do know is that aspects of life that depend upon for joy and comfort, motivation and personal fulfillment, things like physical contact, sensory stimulus, social interaction, variation in our daily activities and interests can be terrifying for autistic children. During this hearing, we will focus on the realties of autism and what we can do to make progress toward prevention and treatment of this disorder.

Our second panel will cover a variety of topics, including adoption of children with special needs, juvenile diabetes, pediatric asthma, and poison control. I will reserve my comments on the adoption issue for the moment and briefly note the importance of other issues we will discuss.

Juvenile or type 1 diabetes is a chronic and degenerative illness affecting virtually everybody's system. Taking insulin doesn't cure diabetes, it merely helps to control it. The range of serious health problems associated with type 1 diabetes is truly overwhelming, blindness, kidney failure, heart disease, stroke, nerve damage; and that is not the complete list. We know a great deal about diabetes, but we still have no real cure. That is why our continued investment in research and development and research and treatment is so critically important.

Pediatric asthma is a chronic and potentially life threatening health condition that affects nearly 5 million children under the age of 18. Asthma can be particularly devastating for children because it can severely restrict their ability to participate in normal physical children's activities. Asthma generates enormous public and private and health care costs. Efforts to reduce the incidence, the prevalence and the severity of asthma are clearly in the best interests of children and the health system as a whole.

Another topic for our second panel is poison control. I was surprised to learn that poisoning is the third most common form of unintentional death in the United States, but not surprised to learn that children are disproportionately affected.

Finally, I would like to touch on adoption of special needs children. Mr. Chairman, I understand that as is standard for these hearings, the majority staff held a briefing last week and discussed the topics on today's agenda. During that briefing, Democratic staff asked whether abortion issues would play any role in today's discussion. They were assured that these issues would not be part of today's hearing.

Apparently, however, Mr. Pierce alludes to that very topic several times in his written testimony that he himself, Mr. Pierce, provided. We are pleased, and we think it very important to discuss the topic of adoption for special needs children as long as adoption and adoption alone, not abortion, is, in fact, what the discussion was about. This hearing is too important to get waylaid in those kinds of ideological issues.

Mr. Chairman, I hope we all share the same agenda today. The topic we are discussing is far too important to be compromised by any secondary motives. Thank you, Mr. Chairman.

Mr. BILIRAKIS. I thank the gentleman. Mr. Greenwood for an opening statement.

Mr. GREENWOOD. Thank you, Mr. Chairman. We will hear statistics about autism from our witnesses, and we have already heard them—previous speakers cite those statistics. Suffice it to say, it is a very prevalent and probably increasingly prevalent disease in our society affecting 400,000 Americans, one out of every 500 children, and the funding and the research that is devoted to this disorder is far less than should be. The reason that I got involved in this really goes back to the fact that I was—used to be a caseworker and worked—I was as a house parent, at one time, and I worked with special needs children.

I watched parents see their children go through what normal children do. The joy of a parent is to watch a child open up like a flower and begin to explore its world and communicate with its parents and the world. For the parent of an autistic child, the parent sees that child open up and then start to close. It is a heartbreaking, heartwrenching experience; and these parents who love these children very much are sort of watching them recede from their touch, are desperate, desperate to fight this disorder, desperate to find a cure, even treatment that will ameliorate the condition.

The reason that Rene Russo is here is because she and I have a mutual friend. His name is Jon Shestack, the gentleman seated to her left. Jon and his wife, Portia, have a little boy named Dov. Dov has gone through this experience and Jon has shared with me his experience, his feelings in very honest terms. What we intend to do is create five centers of excellence where the best scienctists, the best doctors, the best researchers in the world will come to these centers and they will engage in basic research on what causes autism, how to treat autism, how to cure autism, and how to prevent autism. That will mean that parents of children equally concerned and desperate all over this country will be able to find access near their home, the region in which they live to take their children and make sure that their children have every opportunity known to science at the time to do what is best for their child, to bring their child back to that opening flower. I know that Rene Russo was—this is not her usual gig coming to Congress. She said that it was sort of like asking a ballerina to pitch the World Series or something, not what she is known for. But I know that she is here because of her love for a little boy named Dov. We are just delighted to have you engaged in this fight. We are going to win this fight, and we think we have a new lethal weapon in Rene Russo and thank you so much for being here. I yield back.

Mr. BILIRAKIS. I thank the gentleman. Ms. DeGette for an opening statement.

Ms. DEGETTE. Thank you, Mr. Chairman. As someone who cares a lot about children's health, I want to congratulate you for having this hearing today. From a personal perspective as well as a policymaker perspective, I don't think there is anything more important than our children's health and well being. We don't even put a frac-

tion of the funds into it that we should in this country. I want to talk about a couple of the myriad issues that we are going to talk about this afternoon. First of all, as the cochair of the congressional diabetes caucus, I am particularly pleased that portions of this hearing will address juvenile diabetes, type 1 diabetes. This affects thousands of children nationwide. It starts with these children when they are very young and stays with them the rest of their lives. Diabetes currently affects an estimated 16 million Americans. It is the sixth leading cause of death due to disease in the United States, and it is the third leading cause in some minority groups.

I believe that in this country, we are at a critical point in diabetes research. Congress, as it has so often with other diseases, needs to step up to the plate and do the most that it can now that a cure is within reach. Last spring, I visited the Joslin Diabetes Center at Harvard University which is a world leader in diabetes research, and visited with many of our leading scientists who are in the cusp of major breakthroughs in cell research and diabetes management and so many other areas. I believe that this disease could be cured within 10 years if Congress fully funds the diabetes research outlined in the congressionally mandated diabetes research working group. The DRWG recommended $827 million for diabetes research, yet regrettably under the current budget outlined for the NIH Centers for Disease Control Prevention and other agencies, the way that we calculate it, diabetes will be lucky to get $500 million.

This is certainly a step in the right direction, but we are too close to a cure to fail to make a full commitment. Children with diatetes or children with other lifelong diseases need a special focus. They are not simply small adults. My own child, for example, like all children with diabetes, must have two injections of insulin each day and a minimum of four blood tests per day. Think about doing that for 60 or 70 years of your life if you live that long, and it begins to let you know simply what living like this is. That is even if you don't get complications.

I believe that Congress has to expand clinical trials to children who are often left out of promising new approaches to treatments and that the clinical trials need to be properly designed for children so that they are not subjected to undue risk. This is true not just with diabetes but for all diseases in which we use children in clinical trials.

Let me talk about the other issues some of them that we are talking about today as well. The panel discussion on autism, I am looking very much forward to and also the discussion on poison control centers. I have cosponsored legislation introduced by Representative Greenwood on pediatric autism research and by Representative Upton on poison control centers. Both of these pieces of legislation should be passed this year without any delay. I hope this hearing lays the groundwork for committee action.

Briefly, I would like to make the committee aware of today's presence of an expert in the field of development and behavioral pediatrics, Dr. Randi Hagerman who is from Children's Hospital in Denver. She is a leading expert in the fragile X syndrome which is currently the leading identifiable cause of autism. According to Dr. Hagerman, 90 percent of fragile X patients have autism fea-

tures, 50 percent of preschool fragile X children meet autism diagnostic criteria, and 6 percent turn out to have fragile X. I think when you look at this research, the link between autism and fragile X syndrome is undeniable.

Dr. Hagerman is sitting in the back row of the room today. I would have liked to have had her testify at the hearing, but I understand time constraints, Mr. Chairman. So instead I would like to ask the chairman for unanimous consent to offer her written statement in the record, if I may.

Mr. BILIRAKIS. Without objection.

[The prepared statement follows:]

STATEMENT OF RANDI J. HAGERMAN, M.D., PROFESSOR OF PEDIATRICS AND SECTION HEAD OF DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS, UNIVERSITY OF COLORADO SCHOOL OF MEDICINE, CHILD DEVELOPMENT UNIT, THE CHILDREN'S HOSPITAL

I am Dr. Randi J. Hagerman, a developmental pediatrician at the Children's Hospital of Denver, Professor of Pediatrics and Head of the Section of Developmental and Behavioral Pediatrics at the University of Colorado School of Medicine. I have been involved in Fragile X research for the past twenty years, and have written more than one hundred scientific papers and three books on the subject. I am a member of the Advisory Board of FRAXA Research Foundation and the Board of Directors of the National Fragile X Foundation. I have personally evaluated over five hundred families with Fragile X syndrome. Thus, I bring a broad clinical and research experience to this discussion.

I am here on behalf of about 100,000 Americans affected with Fragile X—and their families, which include approximately 1 million carriers—to ask for your help and support for H.R. 1445, which would establish centers for research and treatment of the Fragile X.

There are three main reasons you should support H.R. 1445:

- It is the most common cause of inherited mental retardation and causes a broad range of other problems.
- It is a "research portal" for other brain disorders, especially autism.
- It is the leading-edge candidate for a breakthrough in understanding many other diseases, including autism.

THE MOST COMMON CAUSE—AND MORE

Even though it is relatively unknown by the public, as yet, Fragile X is the most common inherited (i.e, "runs in families") cause of mental retardation. More than that, it also causes a broad range of emotional and learning problems even in those carriers who are affected but not mentally retarded. Fragile X is the leading form of autism of known cause: 90% of Fragile X patients have autistic features, 50% of preschool Fragile X children meet autism diagnostic criteria, and 6% of all autistic individuals turn out to have fragile X. Fragile X also gives rise to anxiety disorders, attention deficit hyperactivity disorder, psychosis, obsessive-compulsive disorder, and many other problems. One in every 250 women in the general population is a carrier for Fragile X and has a 50% chance with each pregnancy of having a child affected by Fragile X.

A RESEARCH PORTAL

Individuals with Fragile X are missing a protein that is critical for normal brain growth and development. Specifically, the Fragile X protein is involved with forming the proper nerve cell connections that occur during learning. When an environmental stimulation occurs, the Fragile X protein is the first protein that a brain cell produces to enhance the connections between brain cells, thus permitting normal development. In the absence of this protein, these changes cannot occur in a normal fashion. Thus, Fragile X holds the key to understanding both normal and abnormal brain development.

The Fragile X gene was identified and sequenced in 1991. Since that time, it has become clear that the type of mutation found in the fragile X gene (FMRI) is similar to that found with more than a dozen other neurological disorders, including Huntington's disease, and myotonic dystrophy, which is the leading cause of muscular dystrophy in adults. Dr. James D. Watson, who received the Nobel Prize for the discovery of the DNA Double Helix recently said, ". . . with the first big public payoff

from the Human Genome Project being the 1991 cloning of FMRI, I want to see this great breakthrough appropriately used . . ."

In other words, Fragile X represents a portal through which we hope to view and treat a wide variety of other disorders of brain development and function. **All children with autism and mental retardation of unknown cause should be tested for Fragile X.**

A LEADING-EDGE BREAKTHROUGH CANDIDATE

Fragile X research is on the leading edge in our understanding of gene-brain-behavior relationships; it serves as a model for many other neurodevelopmental disorders. Moreover, there is real cause for optimism in finding an effective treatment. With Fragile X, the coding portion of the gene is normal, it is just turned off, so no protein is produced from the gene. Thus, we do not need to introduce a new gene; we just need to find out how to turn on the silent gene that is already present. This breakthrough would lead to a cure.

Funded treatment and research centers will help to achieve this goal because they allow a variety of professionals to work together toward the common goal of understanding and treating this disorder. Physicians, psychologists, and therapists must work together with molecular experts to advance our understanding of clinical-molecular correlations, and to develop comprehensive treatment programs. The unusual patients detected by clinicians, those who have the gene partially active, hold the key for the reactivation of the gene. Treatment trials will also require input from both clinicians and basic scientists. Collaborative efforts thrive in centers that are specifically designed and funded for such interactions.

Thus far, individual research grants in the field of Fragile X have not led to treatment research. In 1988, we published the only controlled trial of medication-based treatment for Fragile X, and I believed that this trial would be followed by a rush of additional research focused on treatment. This has not occurred; no subsequent controlled treatment studies have been published. The proposed centers would specifically foster the interactions that would lead to such trials.

IN SUMMARY . . .

Fragile X is an important disorder, because it is the most common heritable form of mental retardation, and the most common known cause of autism. It is a window to a greater understanding of many other diseases involving abnormal brain development and function. It is the leading candidate for a breakthrough in treatment.

Your help in establishing funded centers for Fragile X treatment and research will allow and encourage scientists and clinicians to combine the medical treatments of today with the genetic therapies of tomorrow.

Ms. DEGETTE. Thank you, Mr. Chairman. Finally at a time of relative prosperity in this country, there are some disturbing trends in children's health that I hope the committee will address in the near future. First and foremost, despite—Mr. Chairman, may I have unanimous consent for another minute?

Mr. BILIRAKIS. Without objection.

Ms. DEGETTE. Thank you. Despite children's health insurance as part of the balanced budget act of 1997, the number of uninsured children continues to increase and reached 11.1 million in 1998, according to the U.S. Census Bureau. If we were adequately the CHIP program and the Medicaid program in this country, Mr. Chairman, we could have had nine of these 11 million children enrolled in health insurance today. To address these and other concerns regarding children's health coverage, I introduced H.R. 827, the Improved Maternal and Children's Health Coverage Act. This legislation has 112 bipartisan cosponsors and although today's hearing is not about health insurance coverage, all of these children who have these other issues would be well served by being in health insurance. So I urge the chairman to hold a hearing on health coverage soon, and I would love to see my bill passed. Thank you again for holding this hearing, and I yield back.

Mr. BILIRAKIS. I thank the gentlelady. Mr. Stupak.

Mr. STUPAK. Thank you, Mr. Chairman. I will be brief. I just got off of the airplane from Michigan. There are a couple of bills on the floor so I will be bouncing in and out. But I look forward to this hearing. I hope we can hear the witnesses before I have to go down on the floor and look forward to working with you on this legislation.

Mr. BILIRAKIS. I thank the gentleman. Mr. Ganske for an opening statement.

Mr. GANSKE. Thank you, Mr. Chairman. I am interested in hearing the testimony. I yield back.

Mr. BILIRAKIS. I appreciate that. Mr. Waxman, now, you are really in a spot.

Mr. WAXMAN. Thank you, Mr. Chairman. I am pleased you are holding this hearing. I am anxious to hear the testimony as well. I have to apologize to the witnesses because I also have to be in another hearing at the same time, but the record that you will make I hope will allow us to move forward on important issues dealing with autism, and juvenile diabetes, asthma, and other childhood diseases.

I yield back the balance of my time and look forward to hearing the witnesses's testimony.

Mr. BILIRAKIS. I thank you. I think that we have heard from all members of the subcommittee. Mr. Upton informs us that he wants to be here to particularly talk about his poison control center legislation, but the date-rape bill is on the floor at the same time. He is involved in that. Without objection, his opening statement will be made a part of the record.

And, of course, the opening statement of all members of the subcommittee will be made a part of the record without objection.

[Additional statements submitted for the record follows:]

PREPARED STATEMENT OF HON. FRED UPTON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MICHIGAN

Mr. Chairman, thank you for convening today's hearing on children's health issues. Each of these issues is important to me, but two are especially close to my heart: preventing and treating accidental children's poisoning and reversing the spiraling increase we are seeing in childhood asthma, particularly in our inner cities.

Poisoning is the third most common form of unintentional death in the United States. In any given year, there will be between two and four million poisonings. Poisoning accounts for 285,000 hospitalizations, and 13,000 fatalities yearly. The total direct costs associated with poisoning total $3 billion annually. That is more than we spend on gunshot wounds, burns, or drowning yearly.

Children are disproportionately affected—sixty percent of poisonings involve children less than six. Poison control centers are one of our nation's most effective means of reducing this serious child health problem, offering both parents and health professionals immediate and accurate access to diagnosis and treatment that often leads to a reduction in the severity of the poisoning. Almost 75 percent of calls to the centers can be handled in the home, thereby reducing needless emergency and hospital costs. Every dollar spent on poison control centers saves seven dollars in potential medical costs (per the American Academy of Pediatrics).

As you are very well aware, Mr. Chairman, many poison centers—the front lines in the treatment and prevention of accidental childhood poisons—are endangered. I again and especially want to thank you, my original cosponsor Ed Towns, and the other members of the Subcommittee and full Committee who have cosponsored the legislation I introduced to provide these centers with a stable funding base and to create a national poison hot line.

Chronic asthma is a serious and growing health problem confronting our nation, and particularly our nation's children. The Centers for Disease Control and Prevention reports that 6.4 percent of our population report having asthma—a dramatic 75 percent increase over the last two decades. Childhood asthma has increased even

more dramatically—over 160 percent since 1980—and is the most common childhood chronic disease. It is particularly prevalent among the urban poor, in all likelihood because of lack of access to health care and the high number of allergens in the environment. Asthma deaths have tripled over the past two decades, despite improvements in clinical treatment. In my own state, 5.7 percent of the population, or 542,300 Michiganders suffer from asthma.

I wanted to take this opportunity to briefly describe legislation Henry Waxman and I have introduced to help us marshal and coordinate our resources to much more effectively wage war against this significant threat to our nation's health. H.R. 2840, the Children's Asthma Relief Act of 1999 creates a $50 million program within the Maternal and Child Health Block Grant program to assist communities in areas with a high prevalence of childhood asthma and a lack of access to medical care to establish treatment centers. In addition to providing medical care on site and in various areas of the community through "breath mobiles," the centers will also provide education to parents, children, health providers and others on recognizing the signs and symptoms of asthma, provide medications, and provide training in the use of these medications. The centers will also provide other services, such as smoking cessation programs and home modifications to reduce exposure to allergens.

In closing, I want to welcome all of our witnesses and to note that I especially appreciate Dr. Richard Weisman's willingness to discuss childhood poisonings and the vital role that our nation's poison control centers play in addressing this serious problem.

PREPARED STATEMENT OF HON. TOM BLILEY, CHAIRMAN, COMMITTEE ON COMMERCE

Mr. Chairman, thank you for calling this hearing today. This topic—Children's Health: Building a Better Future—is an important one that calls out for closer scrutiny and examination. This subcommittee is considering a range of issues—each are deserving of our attention. First, today we will examine a heart breaking condition—autism. Autism is a serious disease. Autism is not rare: it affects 1 in every 500 children born today and is more prevalent than Down syndrome, childhood cancer or cystic fibrosis. It hits children during the first two years of life and causes severe impairment in language, cognition and communication.

The next matter before us today is adoption. During my time in Congress, I have always focused on adoption policy and I see great potential for progress in this important area. I especially believe that there is more that we can do to encourage adoption of children with special needs. If children born with birth defects are adopted early, they stand a far better chance in life than if they go through the foster care system.

Juvenile diabetes and pediatric asthma are maladies that cost individuals, families, and society at large dearly. It is important that the Members of this subcommittee listen to this testimony and discuss possibilities for *building for a better future* by reducing the incidence of these diseases among children. We know we can lessen the incidence of child mortality through the use of successful poison control methods. We are told that every dollar spent on poison control centers saves seven dollars in potential medical costs. Let us examine how we can help make these centers even more effective.

Once again, I applaud this subcommittee for conducting a hearing on children's health. We have before us two panels of distinguished guests who bring a wide breadth of perspective. I look forward to their testimony.

Mr. BILIRAKIS. The first panel consists of Ms. Rene Russo, board member of the Cure Autism Now group from Los Angeles, California, and Ms. Francine Young, registered nurse, from Tonawanda, New York.

Ladies, thank you so very much for taking time away from your families and your work to be here. I don't know whether Ms. Young furnished us with her testimony, but in any case, the point is all of your written testimony is a part of the record if we received it. And I will turn the clock on for 5 minutes, and hopefully you can get your story across. Obviously if you need more time, I will give it to you. Ms. Russo, please proceed.

STATEMENTS OF RENE RUSSO, BOARD MEMBER, CURE AUTISM NOW, ACCOMPANIED BY JONATHON SHESTACK, PRESIDENT, CURE AUTISM NOW; AND FRANCINE YOUNG

Ms. RUSSO. Mr. Chairman, I am terrified. I am so excited.

Mr. BILIRAKIS. Please pull the mike closer.

Ms. RUSSO. I am terrified. I am excited to be here. I feel so glad. There are so many emotions coursing through by body, it will be a miracle if I get through it. If I stop to cry, that is who I am. I can't help it. I really do care about kids. Usually I am on the other side of the panel, the one being asked or sometimes guilted into my time and resources. So I know how difficult it is for you to make decisions between schools and foreign aid and roads and who gets it and who doesn't. I said to a few of you, I am thankful that it is your job because I couldn't do it. I really couldn't.

It was very difficult for me to focus on a couple of different charities because they are all worthy. They all need money. I adopted a little boy this year with CF, that I saw die before my eyes. So—oh, boy, here we go. How many minutes do I have here? Here we go. I am going to race through it. I will collect myself.

Having said that, there were a few reasons that I really chose autism. I met Jon and Portia Iverson. They started Cure Autism Now, CAN, several years ago at a lunch and it was at that lunch that I learned that their son, Dov, had just been diagnosed with autism and they had just started CAN. I knew very little about autism but what was amazing to me at that lunch were the statistics. I was very curious about them. I just wanted to run a couple of them to make it very clear for you. Really I am making it simple for myself, but I learned that one in every 500 children have this disease or diagnosed every year. That is 400,000 people in the United States. It is more common than multiple sclerosis, Downs syndrome or cystic fibrosis.

I remember sitting and thinking, I wonder why I haven't gotten a letter in the mail to head up a fund raiser if it is so prevalent. I hadn't heard of it yet there were so many kids that had it. We are not sure if it is a real epidemic or better reporting, but we do know that in California, where I am from, the Department of Developmental Services reports a 263 percent increase in autism in the last 10 years.

We found out this week that in Florida there has been a 500 percent increase. That is terrifying to me. It is terrifying for the kids that are here and the ones that aren't. I also learned at that luncheon that as of 3 years ago, the funding was $5 million. That is less than $12 a person, even though autism is estimated to cost the country some $13 billion a year. I remember sitting there and thinking, wait a minute, if this disease is more common than the three big childhood diseases, then why is it so underfunded? And Portia and Jon explained a little bit of the history of autism. It has been ignored to so long because in the 1950's the medical community thought that it was bad parenting, trauma, neglectful mothers. So obviously the parents were stigmatized and never moved forward to organize and the scientists did no research. So a generation of children were lost. Gradually they realized autism was a medical problem, but they thought it was incurable. So scientific knowledge grew all around the disease, but it was never applied to

autism. When Jon and Portia's son was diagnosed with autism, it took 6 months and five different specialists to be told there is nothing to be done.

Damn. Sorry.

But to hold onto each other and cry and then to move on with their lives.

God. This is by far the hardest thing I have ever done. Okay. A mother handed me a note that she wanted me to read to you. She said, when our son was diagnosed 3 years ago, we were told he had a chronic incurable condition. There was no protocol for the treatment, no specialists at all. The doctors said all we could do is start educating ourselves, start searching. And even today, a parent is being told the awful news; and there is nowhere for them to go. So they were told to start educating themselves, but there is not a whole lot of information out there.

Jon and Portia went to the NIH at that point, and that is when they found how little money was being spent on autism and how little information there was on the disease. So what they decided to do was go to the neuroscientists themselves—God bless parents—and they all said the same thing, that there was an unbelievable potential for progress even with the limited information and with the best minds and latest technology early detection, prevention, better treatment and even a cure was possible.

So they were hopeful. They organized thousands of families. They went back to NIH, and unfortunately what they found was because of turf battles and scientific competition nobody wanted to share what they had. They were back to square one. So the families organizing went back into the community and started their own brain banks and gene banks so that more people could get into the field. That brings us to the present.

How am I doing, pretty good? I think I have a minute left here.

We are not asking you to tell the NIH how to do science or to fund and what not to fund and, but we are asking you to create a policy that would take advantage of what is known now, to help the scientists work together and help these kids. That is the idea behind the Centers for Excellence, the five Centers for Excellence, a place where families can go and get a diagnosis, some hope, clinical care. Where the very best scientists can get together and access those families to finding a cure.

The purpose behind Congressman Greenwood's bill is to create a structure that encourages scientists to collaboratively share information and treatments because early diagnosis for these kids is very important to their future. It is the difference between a word and a functioning human being. This was the same model that was used to make incredible breakthroughs in childhood leukemia and Alzheimers.

In childhood leukemia, for instance, it went from a 20 percent to 80 percent survival rate. So we are basically stealing that model. Recently the autism community has mobilized, and they do feel potential for a breakthrough, but we need the money. We need your help. Because these kids, half of these kids will never learn to talk or go to school; and they will never live independently. Many of them will end up in institutions and group homes.

I can't tell you how many parents don't have the time or energy or resources to help these kids. We think that the parents are taking care, but they don't know where to go. I know every parent's pain is deep and that every disease has its own suffering, but in autism the neglect has been so severe and the potential for progress so great that it would be tragic to do nothing.

Two years ago, we did a fundraiser that raised $250,000. That was a big deal for us. At that time and at the present, that is the most money that we have ever raised at one event. This is a disease that affects over 400,000 people. I don't need to sit here and tell you how painful it is for parents because we are all parents, and we can imagine that. But I remember one parent saying to me that it was like someone crept into her son's second birthday into her house and took her baby's mind and personality and left his bewildered body behind.

I love you.

I think if one in 500 kids were actually being abducted in the United States, it would be a national emergency; and I think this should be. So thank you so much for your time. God bless you all and thank you so much for having me.

[The prepared statement of Rene Russo follows:]

PREPARED STATEMENT OF RENE RUSSO, BOARD MEMBER, CURE AUTISM NOW

Mr. Chairman and Committee Members, I feel blessed to be here today. Thank you for this opportunity. I'm usually the one on the other side of the panel, the one being asked, sometimes guilted, into giving my time and resources to yet another worthy cause. As you know, it's a real challenge because they're all heartbreaking and they all need money. I don't know how you decide day after day between schools, foreign aid, roads—who gets it and who doesn't. God bless you all. I'm glad it's your job. I'd end up in the loony bin.

Having said that, it was a real challenge for me to make a decision what to support given limited time and resources.

I met Jon and Portia several years ago at a luncheon with some mutual friends. At that lunch I learned their son had recently been diagnosed with autism, and they told me how they had just started Cure Autism Now. To be honest, I knew very little about autism. What was amazing to me were the statistics, the numbers about the disease.

Here's what I learned:

—Every year autism affects 1 in 500 children.

—That's 400,000 people in the United States.

—And it's more prevalent than multiple sclerosis or downs syndrome or cystic fibrosis.

I remember sitting there thinking gee, I wonder why I haven't gotten a letter in the mail asking me to head a fundraiser for autism given it's so prevalent.

We're not sure if there's a real epidemic or it's better reporting but we do know that in California, where I'm from, the Department of Developmental Services reports a 263 percent increase in autism in the last ten years.

What was also amazing to me about that luncheon was that the funding for autism, as of two years ago, was $5,000,000. That's less than 12 dollars a person even though autism is estimated to cost this country some 13 billion a year.

So I'm sitting there thinking wait a minute. If this disease is more common than the three big childhood diseases, then why is it so underfunded?

The reason that has been ignored for so long is that in the 1950s, when scientists first started describing autism, they blamed it on bad parenting, trauma or neglectful mothers.

Parents were stigmatized so they never organized and serious scientists did no research. A generation of children was lost. Gradually they realized autism was a medical problem, but they thought it was incurable. Scientific knowledge grew all around the disease, but were never applied to autism.

When Jon and Portia's son was diagnosed with autism, it took six months and five different specialists to be told there's nothing to be done but hold each other

and cry and then move on with your lives. That was it. No hope. No advice, just ignorance.

They didn't accept that answer. They explored every therapy, every theory—everything you would do for your child. When those didn't work, they said there must be something new. But it simply didn't exist.

Jon and Portia went to the NIH and that's when they found out how little was being spent on autism and how little information there was on the disease.

What they decided to do was go to the neuroscientists themselves. They all said the same thing. There was an unbelievable potential for progress. With the best minds and latest technology—early detection, prevention, better treatment and even a cure was possible.

After organizing thousands of families themselves, Jon and Portia went back to the NIH and what they found was that because of turf battles and scientific competition, nobody wanted to share what they had. They were back to square one.

Can went out into the community and started their own brain banks and gene banks so more people could get into the field.

Which brings us to the present. We're not asking you to tell the NIH how to do science, what to fund and what not. We're asking you to create a policy that takes advantage of what is known and use it.

That is the idea behind centers for excellence—a place that families can go to get a diagnosis and clinical care and the very best scientists can get access to those families. The purpose behind this bill is to create a structure that encourages scientists to work collaboratively, sharing information and treatments.

This was the same model that was used to make incredible breakthroughs in childhood leukemia and Alzheimers. In childhood leukemia the survival rate went from 20 to 80 percent.

Recently, the autism community has mobilized. They feel the potential to make a major breakthrough is here.

But they need your help.

Because half of these kids will never learn to talk or go to school. They will never live independently. And many will end up in institutions or group homes.

I know that every parent's pain is deep and that every disease has its own suffering, but in autism the neglect has been so severe and the potential for progress so great, that it would be tragic to do nothing.

Two years ago we did a fundraiser that raised $250,000, and that is, at present, the most money ever raised at one event for autism—a disease that affects over 400,000 people.

Look, I don't need to sit here and tell you how painful it is for parents because we're all parents and we can imagine that, but I remember one parent saying that it was like sometime before her son's second birthday someone crept into her house and took her baby's mind and personality and left his body behind.

If one in 500 kids were actually being abducted in the United States it would be a national emergency, and so should this be.

Please pass Representatives Chris Smith and Jim Greenwood's bill out of this committee and send it on to the house floor this year. Please allow these families to have hopes and dreams for their children again.

The potential is there. With your help, it will happen.

Thank you.

Mr. BILIRAKIS. Thank you, Ms. Russo.

Ms. Young, please proceed.

STATEMENT OF FRANCINE YOUNG

Ms. YOUNG. Thank you, Mr. Chairman and Mr. Brown and all other members of the subcommittee for giving me this opportunity to talk about autism. Mr. Chairman, I would also like to publicly thank my Congressman, Mr. LaFalce, for helping me to arrange my appearance here today. Congressman LaFalce received a letter from the Autism Society of America last Friday supporting my testimony and thanking him for his interest in autism. The letter also enclosed from other parents across the country to support the increased funding for autism research. I hope the letter can be included in the hearing record.

Mr. BILIRAKIS. Without objection, it will be.

Ms. YOUNG. I am here——

Mr. BILIRAKIS. Please move your mike closer. Do the best you can. I know it is tough for you.

Ms. YOUNG. Thank you. I am here to speak for the children because they cannot speak for themselves. I am a registered nurse of 18 years, and my son, Douglass Young, Jr., is our pride and our joy. As with any parent, your love for your child surpasses life itself. My son was born a healthy baby boy December 11, 1996. In May of this year, he was diagnosed with autism. Being from the medical profession, I insisted on a battery of tests to rule out other possiblities before accepting that diagnosis.

As you can imagine, the news was devastating. It was as if someone just ripped my heart out of my chest because presently there is no cure. At the time of the diagnosis I felt helpless and very alone in my sorrow. Like any other mother I would give my life gladly in exchange for my child's health. I would climb any mountain and go anywhere to save my baby. As a registered nurse, I know that at this time autism is a lifelong disability where the prognosis is unknown. Small strides have been made against autism, but there has been no new treatment in the last 25 years developed by the medical profession. This is a travesty for parents, families and children. Only if you are the parent of an autistic child can you understand the pain. I talked to other mothers and fathers with autistic children and our common saying is we are walking in these shoes, but they hurt too much. I would love to take them off. Just because our children cannot talk, doesn't mean they have nothing to say. If they could, they would be crying, please help me.

Imagine for a moment your baby not calling you mom or daddy. Imagine for another moment your child needing you, but unable to call out for help. It is as if they had a stroke. They know everything going on around them and can't make their feelings known. They can't tell us if they are hungry or have a sore throat. They can't express their wants through verbal communications. When you call them it is as if they are deaf, retreating to a world of their own. They cry sometimes for hours on end and they cannot be consoled because they are in physical pain brought on by chronic gastrointestinal problems and other problems. When you are out in public it is hard to explain their peculiar behavior because physically they look absolutely normal.

How many other families and children must feel the pain? My 5-year-old daughter always asks me, why doesn't Dougie talk; why doesn't he play with me? How do you answer those kinds of questions? I am scared for my son's future. How will he be treated. Will he ever get married or have a family. Those answers lie with you because if these bills are passed, we may find the cause and help our babies. So that maybe this disorder can be a disorder of the past. If this is an outbreak of small pox, we will be all over it. But because these children have no physical handicaps, we tend to forget them. I love my son, and so do all of the parents of autistic children. Please, I beg you, help us by passing bills H.R. 274 and H.R. 997.

Excuse me.

The Los Angeles Times August 16, 1999, headlines, State Reports Epidemic of Autistic Children. Dr. Bernard Rimland of the Autism Research Institute in San Diego says we are in the middle of an autism epidemic.

It has already been stated that one in 500 children are autistic according to the National Institutes of Health. Recent reports in New Jersey are telling of autistic clusters affecting 1 in 150 children in California. One child is being diagnosed as autistic every 4 hours or 6 children a day. I have more, but you can read that later. On October 7, 1999, the Miami Herald reported the Florida Department of Education has documented a 563 percent increase in autism in the last 10 years. The U.S. Department of Education has reported an increase of autism in every State. There is no such thing as a genetic epidemic. We are losing a generation of children. We cannot allow this to continue in our great Nation. We need to find a cure. We have to know the causes and determine which types of autism can be prevented. We have to have the guidance of qualified physicians when your child is diagnosed with autism. They say sorry, Mrs. Young, but there is no cure, and we really don't know how to treat him. You are pretty much on your own to see which stone age treatment will work best.

These children need to have proper medical care as early as possible. We need to accelerate our biological and immunological research. These children have been ignored for so long. Parents are going bankrupt refinancing their homes and trying every treatment under the sun for the small chance their child might be helped. For every child diagnosed with autism, estimates are showing that it will cost $2 million for a lifetime of care.

In closing, I want you to look at my son. Here is a picture, my love of my life. This could be your child or your grandchild. No one in this room is immune to autism, no one in this room. It knows no color, no race, no color and no creed. If we continue to ignore this disorder, we will all be mourning our children and one day be saying to ourselves, why didn't we listen. Why didn't we care.

Don't let this happen to your child or grandchild for the pain is too unbearable. Let's attack it before it grabs another baby's life. You are in a position and the only ones that can help them. For the children, pass these bills. Please look at my baby one more time and don't say no to my son or anyone's autistic child. Thank you. Thank you.

[The prepared statement of Francine Young follows:]

PREPARED STATEMENT OF FRANCINE YOUNG

Thank you Mr. Chairman and Mr. Brown and other members of the subcommittee for giving me this opportunity to talk about autism. I am here to speak for the children because they cannot speak for themselves.

I am a registered nurse of 18 years and my son Douglas Young Jr. is our pride and our joy. As with any parent: your love for your child surpasses life itself.

My son was born a healthy baby boy Dec. 11, 1996. In May of this year he was diagnosed with autism. Being from the medical profession I insisted on a battery of tests to rule out all other possibilities before accepting that diagnosis.

As you can imagine: the news was devastating. It was as if my heart was just ripped out of my chest. Because presently there is no cure. At the time of the diagnosis I felt helpless and very alone in my sorrow. And like any other mother I would give my life gladly, in exchange for my baby's health. I would climb any mountain or go anywhere to save my baby.

As a registered nurse I know that at this time, autism is a lifelong disability, where the prognosis is unknown. Small strides have been made against autism. There has been no new treatment in the last 25 years, developed by the medical profession.

This is a travesty!! For parents, families, and the children. Only if you are the parent of an autistic child can you understand the pain. I talked to other mothers and fathers with autistic children: and our common saying is: "We are walking in these shoes... but they hurt too much. I'd love to take them off."

Just because our children cannot talk, doesn't mean they have nothing to say. And if they could: they would all be crying: "please help me"!!

Imagine for a moment your baby not calling you momma or daddy. Imagine for another moment, your child needing you, but unable to call out for help. It's as if they had a stroke!! But they know everything that's going on around them, and can't make their feelings known.

They can't tell us if they're hungry, or if they have a sore throat. They can't express their wants through verbal communication. When you call them, it's as if they're deaf. Retreating to a world of their own. They cry sometimes, for hours on end, and they cannot be consoled. Because they are in physical pain, brought on in part by chronic gastro-intestinal problems.

When you're out in public it's hard to explain their peculiar behavior, because physically they look absolutely normal.

How many more families and children must feel the pain?? My 5 year old daughter always asks me: "momma: why doesn't Dougie talk?? Why doesn't he play with me??" How do you answer those kinds of questions?? I am scared for my son's future. How will he be treated?? Will he ever get married and have a family?? Those answers lie with you. Because if these bills are passed, we may find the cause and help our babies, so that maybe this can be a disorder of the past.

If this was an outbreak of smallpox we would be all over it. But because these children have no physical handicaps and look so normal, we tend to ignore it. I love my son and so do all parents of autistic children. Please, I beg you, help us by passing these bills.

The Los Angeles Times on August 16, 1999 (headlines): State reports epidemic of autistic children. Dr. Bernard Rimlind of the Autism Research Institute in San Diego says we are in the middle of an autism epidemic. 1 in 500 children are autistic according to the National Institute of Health. Recent reports in New Jersey are telling of autistic clusters, affecting 1 in 150 children. In California: one child is being diagnosed as autistic every 4 hours, or 6 children a day.

In Virginia, a 27 percent increase of autism over the past few years has been documented. The Inland Regional Center in California reports that 2 counties: San Bernardino and Riverside, are reporting 150 children, diagnosed with DSM4: which is full blown autism every month. The Miami Herald on October 7, 1999 reported that the Florida Department of Education has documented a 563 percent increase in autism in the last 10 years. The U.S. Department of Education has reported an increase of autism in every state. There is no such thing as a genetic disease epidemic.

We are loosing a generation of children.

We cannot allow this to continue in our great nation. We need to find a cure, have to know the causes, and determine which types of autism can be prevented. We have to have the guidance of qualified physicians. When your child is diagnosed with autism, they say sorry Mrs. Young, but there is no cure. And we really don't know how to treat him. They have no clue.

You're pretty much on your own, to see which stone-age treatment will work the best. These children need to have proper medical treatment as early as possible. We need to accelerate our commitment to biological and immunological research.

These children have been ignored for so long, parents are going bankrupt, refinancing their homes, trying every treatment under the sun. For that small chance their child might be helped. For every child diagnosed with autism, estimates are showing that it will cost 2 million dollars, for a lifetime of care.

In closing: here is a picture of my baby son. My love... my life. This could be your child, or your grandchild. No one is this room is immune to autism. It knows no race, no color, no creed. And if we continue to ignore this disorder, we will all be mourning our children. And one day be saying to ourselves: "why didn't we listen?? Why didn't we care??"

Don't let this happen to your child or grandchild. For the pain is too unbearable. Let's attack it... before it robs another baby's life. You are in the position, and the only ones, that can help them. For the children: pass these bills. Please look at my baby, look long and hard, and don't say no to my son. Or anyone else's autistic child.

Thank you.

Mr. BILIRAKIS. Thank you, Ms. Young and Ms. Russo. Obviously, the testimony from both of you is very moving. Our hearts certainly go out to you, Francine, and our gratitude to you, Rene, for caring and for putting your energy and your time behind your caring, not just the money but the energy and the time which is sometimes even much more important.

Ms. Russo, can you describe, if you know—if you don't know, I would like—CAN, the organization to describe to us the effort that they have taken to start their own gene and brain banks and how do such banks work and how are they helpful to the advancement of clinical understanding and improvement of autism.

Ms. RUSSO. I do know a little bit about it but I think it would be wonderful for Jon, because he is really great——

Mr. GREENWOOD. Mr. Chairman, can I ask unanimous consent that Mr. Shestack help her with that question?

Mr. BILIRAKIS. I guess I have no problem with that. It is out of the ordinary, but please do that. Again, you are not going to have enough time to go into it with any detail, but I would like to ask that you submit that information to us. It can be very helpful.

Mr. SHESTACK. Thank you, Representative Bilirakis, for the opportunity. Because autism research was so behind for so long, scientists didn't have the basic tools they needed to make progress which was tissue from people, often brains which is the real tough subject and also DNA which is blood from multi-plex families. There wasn't enough to go around and when people had it, they didn't share it. So what has happened recently the families from the various groups, from NAR, with the brain bank and from CAN with the gene bank, have taken these matters into their own hands and created these resources with their own money that they have raised from families and made this available to scientists all around the world. For instance, with the gene bank in 1 year the families from CAN contacted 500 families who had two kids with autism or more. They got to these families and took their blood and put it in a repository so now everybody can have it. No one has to go through that cost or expense to get it. We hope that this will move science much faster. What we have been trying to do is prime the pump and get it as ready as possible for to you take it over and to help us. So that is why we have been funding pilot studies and research and doing everything we can to bring scientists in to create these resources. And the Internet and modern technology has made this possible in ways never before.

Mr. BILIRAKIS. How do the brain banks work?

Mr. SHESTACK. People from NAAR know more about it, but what happens is alerts are sent out to families and to physicians and to hospitals all around the Nation. In the event of a tragic death of somebody with autism, if the family consents and they need know about it in advance, they make sure that brain becomes available. For instance, I love my 7-year-old son more than anyone could love anyone in the world, but the truth is, if he were to die tomorrow, we have worked all these years to help him and we would want to make sure that in the horror of his death there would be some good that would come of it. So we would do everything that we could to make sure that that brain would get into the hands of as many scientists as possible immediately as possible.

What we do is we let families all around the Nation know about this and know how very important it is. What the scientists tell us is what they need is money and time and the raw materials to do the work. That often means DNA and tissue. Without it, they can't do it. The same—the DNA is much easier to get. They just come to the home and get a blood sample. But right now, people can do whole genome scans in 6 months. People every day pick up your paper and they see another gene discovered. Fragile X, a very important finding in red syndrome, was made the other day, and this is because large collections of DNA were made available to many scientists. This is the way that it is going to be done in the future. No group is going to be able to hold it back anymore. They are going to have to share it with the public and with the world. It is the only way to move things fast.

Mr. BILIRAKIS. Does CAN have or does any other organization have a list, a roster, whatever, if you will, of families with, unfortunately, with this problem?

Mr. SHESTACK. Sure. All of us have our mailing lists. The Autism Society of America, for instance, has a registry. It is working on thousands of families that want to participate in research. We have a list, it is confidential and anynomyzed of 500 plus families with more than one child, sometimes two or three with autism. So what we are all doing is going out into our own communities and saying now there is a real opportunity. Ten years ago maybe there wasn't, but now we can solve this. And we are trying to organize ourselves and put us in a position to best take advantage of these centers of excellence. We are cooperating among ourselves and trying to suggest that you help set up a system at the NIH for scientists to help as well.

Mr. BILIRAKIS. Thank you. Mr. Brown is recognized.

Mr. BROWN. Thank you, Mr. Chairman. I don't know specifically, this is not addressed to any one of you in particular, but any of you that can can answer it. Is there any evidence that any racial group or demographic group or any demographic group on poverty, gender, anything that you can tell us? Certainly there are geographic issues involved, but can you comment on any of that?

Ms. RUSSO. There may be geographic issues, but, no. That is what we don't know. That is why we need the science. It just hits across the board.

Mr. SHESTACK. That is correct. Autism strikes all racial groups, all economic groups, all religions, all creeds, all nationalities. The only thing you can say economically is taking care of—if you weren't poor to begin with, you will be poor.

Ms. YOUNG. You will become poor.

Mr. BROWN. In the geographic disparities, Ms. Snyder from Philadelphia mentioned to me talking before our conference outside that in I believe Montgomery County, Pennsylvania, or at least in her community inside Montgomery County it was 1 in 200. Ms. Young, I think that you said the increase was in 500 percent in California——

Ms. YOUNG. And it does affect more boys than girls.

Mr. BROWN. We do know that for sure, but we don't really know, whether it is chemical plants, pesticides or lawns or agricultural, we really don't have any information at all?

Ms. YOUNG. In New Jersey, it is mostly industrial. They also found a cluster in Granite, California, which is a totally opposite environment. So if you are looking for pollutants, I don't know if you can make a connection because they are totally opposite.

Ms. RUSSO. I think that is the important part of this bill. That is the research that we need.

Mr. BROWN. What age is it? At what age is it most commonly diagnosed?

Ms. RUSSO. Two, around 2½.

Mr. SHESTACK. Actually, if I could, autism comes on sometimes between 18 months and 2 years old. But often a family doesn't get diagnosed, particularly if you go to a boy, because you go to the doctor and the doctor says boys speak slowly. Don't worry about it, he will grow out of it. But they don't——

Mr. BROWN. More likely to have it diagnosed later, I assume. Are the symptoms always there prior to the age of 3 or 4?

Ms. YOUNG. Mine did not have infantile autism. I had a developmental pediatrician look at his tapes prior to up until about 13 months and there was no signs. He was saying mommy, he was saying daddy, he was saying go, up, car. Then everything stopped.

Mr. BROWN. Then the development is arrested or reversed?

Ms. YOUNG. Right. They regress.

Mr. BROWN. Are the major drug companies in this country doing any appreciable research or leaving it up to the government?

Mr. SHESTACK. The drug companies in this country are not doing any appreciable research. Until the last several years, what the drug companies have done recently is support groups like CAN and the national alliance for autism research to help them do pilot studies. In that way they have been generous the last couple of years, but that is $30,000 or $60,000 a study. None of them that I know of have any emphasis on autism yet. As you know, the drug companies are not encouraged to do any work in pediatric illnesses. We all think that kids get good care because sick kids are so sad and so pathetic. But, in fact, the opposite is true. The children get the worst care from physicians, from the Federal Government, and from the pharmaceutical companies because they aren't there——

Mr. BROWN. This society doesn't put many resources into their children. We don't pay people well that take care of children, we don't seem to have in this society the kind of interest that we should in the young. Have you asked the drug companies particularly someone, Ms. Russo, with your stature and name, to ask the drug companies about—I mean, sending a letter to all of the major drug companies asking them to do research?

Ms. RUSSO. We had that meeting, that discussion last night so we are on that front. There are so many things. I am doing something right now that I am helping in the way that I can, but we had that discussion last night about just that thing, that idea.

Mr. BROWN. Thank you. That is all, Mr. Chairman. Thank you.

Mr. BILIRAKIS. I thank the gentleman. Mr. Greenwood.

Mr. GREENWOOD. Thank you, Mr. Chairman. Thank you very much. That was very hard for each of the witnesses I know, and we honor you for being here and doing that. I requested to double the funding from $30 million to $60 million. Money is all relative and numbers are relative, but I just wanted to note for the record

last year we spent $148 million researching obesity. We spent $116 million researching sleep disorders. I don't want to hear from those groups because I am not suggesting that we decrease either of those lines, but I think in just reflecting on the pain that was expressed by the witnesses, by Mr. Shestack, and—you can't see behind you, ladies, is that everybody else is crying at the same time.

Just to honor that and to put things in the proper perspective, going from $30 million to $60 million is not asking a heck of a lot in a budget that is $1.7 trillion a year. I also would just like to note a couple of guys in the audience. One of them is David Greigo. Is David still here? Stand up and wave. How are you doing, buddy? And also—good for you. Also John Harding. Are you still here? Stand up and wave, John. These are friends of mine from my district. David Greigo is the son of Amby Warden and Jerry Greigo, people that I met when we all worked in the same case work office. I married the lady next door to my office and so did Jerry. And Mrs. Harding is from our district.

I am convinced that we could do this. I am convinced that the funding is available. We have a huge surplus. We can afford to do this. We are going to do this and the thing that is exciting to me is the notion that we are going to have a place, five places at least in this country for starters, where every parent can take their children and make sure that no stone is left unturned. And that is our commitment. I am delighted that we are joining this effort with the other measures because I think we are going to build some synergy here. I think all of the groups who are interested in their piece of this bill will become one vast army across the country and see this thing through. I thank you for joining us, and I don't need to ask you any more questions. Thank you so much for being here.

Mr. BILIRAKIS. Ms. DeGette, to inquire.

Ms. DEGETTE. Thank you, Mr. Chairman. I want to echo what Mr. Greenwood said. Let me put this into a little bit of perspective. I just found out earlier this afternoon that the defense appropriations bill that we are talking about, the newest proposal is about $9 billion over the President's request including a whole bunch of experimental fighter planes.

I am not against defense, we need a strong defense in this country. But it seems to me that when you are talking about kids who are the future of our country and they are your kids, my kids, all of these kids. It is not—I mean, autism—I have friends who have autistic kids. As a parent you know what it is like. I have friends who have kids who have all kinds of other terrible conditions as well. We are going to put $9 billion into defense it seems to me when we are all fiscally responsible and trying to have a balanced budget and trying not to raid Social Security, we have to make choices in this country. You can't have everything. It seems to me the thing that we want is a healthy generation of kids.

The other thing that I will say having worked on diabetes issues, we are so close in so much of this research. Doctor, I know that you can confirm some of this. A lot of the research goes across different diseases, it goes across different disciplines. So if we can have basic research, basic cell research, a lot of times this will help. Also we need as my colleague, Mr. Brown just said, we need to beef up environmental research with CDC because we don't

know if this is completely genetic, environmental factor, whatever. Thirty million dollars or $247 million or whatever, it is not even one fighter plane. This is my view. Ms. Russo, the one thing you said that I want to stress that we really need to do is we need to collaborate and work together across disciplines and across NIH and all other research agencies. That is how we are going to solve these problems. Thanks for coming. It is not easy what you are doing, but you have a lot allies in this fight on both sides of the aisle. Both Republicans and Democrats care a lot of about kids' health. These guys know that if they don't pay attention to it, they have got me to deal with. I am a mom. So thanks for coming. I yield back, Mr. Chairman.

Mr. GANSKE. Thank you, Mr. Chairman, and thanks to the panel. It has been a tough day of testimony for you, I am sure.

I just would ask a general question, since we are looking at money for research, do you have any suggestions for avenues that ought to be explored or ways in which we ought to be looking at funding additional programs?

Mr. SHESTACK. The answer is no actually. We would like the scientists at NIH to make those most specific suggestions. That is not what we are here for today. We are suggesting perhaps that they look at it harder and create a policy that is more geared toward success. But we would not suggest which avenues would be the most promising, because the people at NIH are actually very qualified to do that. We need you to give them the tools and the push to do it more.

Mr. GANSKE. Sometimes parents of a child with an illness become quite expert in reading everything they can about what is going on. My sister, for instance, has a little boy with Down's syndrome, and she is pretty knowledgeable about that disease.

I wonder, Ms. Young, you are a nurse. When you look through literature and reviewing studies, are you seeing any hope?

Ms. YOUNG. Well, because it is so—because nobody has done very much research on it. Back in the 50's, what they used to do, we used to institutionalize these children. I am just thinking that everybody's immune system is different, and I think immunological studies should be done. That is my own personal opinion, and biological studies.

Mr. SHESTACK. You do make an excellent point. Parents of sick children, particularly something like autism where there is not that much information, do become instant experts. In autism there has been this terrible break between families and physicians, because there was misdiagnosis and mistrust for so long. One of the things, for instance, that this legislation does is it forces these two communities together, because it is true, parents do notice things that are not in the literature. For instance, if it is gastrointestinal or kids who don't sleep or seem allergic, they notice all sorts of things. So one of the things that this bill does is force clinicians and parents and scientists to have an exchange of information so that they can glean this information from the families, because it is true, the families are the best observers. But beyond that, we feel there are many qualified scientists, and hopefully more every day who will go into this field and take it further.

Mr. GANSKE. Thank you very much.

Mr. BILIRAKIS. Mr. Stupak to inquire.

Mr. STUPAK. Thank you, Mr. Chairman. Reviewing your testimony, and thank you all for coming, very good testimony, you indicated these increases, 563 percent and things like this, Ms. Young, I think you had in your testimony. Is it better diagnosis, better reporting? Why do we see these big increases now?

Ms. YOUNG. I really don't know. All I know is that every time I turn around, I run into a parent who has an autistic child. I have been a nurse for 18 years. It was very rare 18 years ago, and it seems like every time I turn around, not because I am a parent of an autistic child, I am running into someone with an autistic child under 2 years old. I don't think it is better diagnosis. I think something is going on here, and something is going on that is causing the rise in autism. It is just not diagnosis. There is something going on. We have to find what that is going on. Because if it is 1 in 500 now, and it was 1 in 10,000 so many years ago, obviously something is going on and we have to find out.

Mr. GREEN. If the gentleman will yield for 15 seconds, one of the important components of this package introduced by Mr. Smith is the Center for Disease Control tracking.

Mr. STUPAK. Ms. Young, you also said there is no such thing as a genetic disease epidemic. Explain that more. What do you mean?

Ms. YOUNG. If something is genetic, you carry it through your genes.

Mr. STUPAK. It is people saying it is a genetic thing?

Ms. YOUNG. I think part of it is due maybe to genetics, but I think something is triggering it, maybe laying there dormant, something in the environment, something out there. Something we are doing is triggering autism in these children. I am just really frightened.

Mr. STUPAK. This big increase you have seen, has it been in the last 5 years, 10 years?

Ms. YOUNG. I would say within the last 10 years, but in the last 5 years, I think it has been more dramatic. If you look through research, communities all over the country are reporting autism, because we are not keeping good statistics. California keeps great statistics, but New York you could try—I tried desperately before I came here to get some actual figures, and——

Mr. STUPAK. You mentioned Florida, and I don't take issue with your numbers, Florida said 563 percent.

Ms. YOUNG. Miami Herald.

Mr. STUPAK. Did the health officials in Florida verify that number?

Ms. YOUNG. I read it in the Herald October 7th.

Mr. SHESTACK. I can speak about the California statistics. We are not saying these are the best scientifically deduced epidemiological statistics. They are not. That is why we need this bill. However, the Department of Developmental Services in California reports 263 percent increase of people just with autism. Mind you, there are also people with something called Asperger's Pervasive Developmental Disorder, which are on the spectrum which have also increased. What we do know is there are more people with autism than we ever knew were there before. A percentage of this might be due to better reporting, but the other numbers of cerebral

palsy or mental retardation, for instance, did not have a similar increase at all. One would expect if there were better reporting of mental disorders in children as the stigma was removed, there would be increase across the board. This increase has really been restricted to autism. It seems to be this way in every State. But the numbers are primitive, because they are coming from education departments and not from epidemiological centers.

Mr. STUPAK. In the past children with autism, if they were not diagnosed as autism, what would be the misdiagnosis?

Mr. SHESTACK. Something we often say is autism is where Alzheimer's was 15 years ago. Fifteen years ago you might say your grandmother was senile, whereas she had a disease called Alzheimer's. Twenty years ago people with autism might have been called retarded or severely emotionally disturbed. I am sure that our institutions are filled with adults who are also somebody's children in their thirties, forties, fifties and sixties, who have actually what would have been rediagnosed as autism. That alone cannot account for these astronomical rises.

What we are just saying is figure out what it is. Is there an environmental cause? Is there a lifestyle? Is there—whatever it could be, we don't really know. There isn't a big clue. The biggest clue is the numbers are rising. That is the first thing you have to look up and notice.

Ms. YOUNG. I am really scared if we don't take care of it now. Being a nurse, within the next 10 years, I don't know what you are going to see. It might happen to all of you up there, your grandchildren, somebody. We have to take care of it now. It is too heartbreaking.

Ms. RUSSO. I met three people this month who told me their child was diagnosed with autism, and one was my nanny, my daughter's nanny, who has been with me for 10 years. So it really got close to home.

Mr. STUPAK. So with the surplus, instead of tax breaks, we should do more research, right?

Ms. YOUNG. I don't want my taxes back. Find a cure for my kids. And I am not rich. I am not rich.

Mr. STUPAK. Most people would agree with you.

Mr. BILIRAKIS. The gentleman from Ohio, Mr. Strickland.

Mr. STRICKLAND. Thank you, Mr. Chairman. I was struck by the information that is here regarding the amount of money that is currently going into research. Quite frankly, I was surprised to see this. I think Dr. Ganske asked a very relevant question a few moments ago when he said do you have any ideas as to how we can pay for this.

I think it is a relevant question. But I am not sure you are the ones who should be charged about providing an answer. I think your responsibility is to bring to us information based on your experience and your research, and our responsibility as elected representatives of the people is to seek some solution to the information that you bring to us.

So you didn't answer the question, but I would like to try to answer the question in part at least.

Mr. GANSKE. Would the gentleman yield? I am sorry, but I did not ask that question. I didn't ask how can we pay for this.

Mr. STRICKLAND. I thought I said do you have some ideas as to where resources may come from? Am I wrong there?

Mr. GANSKE. Yes, you are wrong. I asked the question do you have any idea where we should put the resources in terms of the research.

Mr. STRICKLAND. I am sorry. I misunderstood that. But having acknowledged my misunderstanding of what you said, I think what I was beginning to say is still relevant.

We support and pay for what we believe is important, and the major responsibility facing us as representatives of the people is to set priorities, and we constantly have to choose between or among things that are very important, terribly important, and I think Representative DeGette was right when she said that there is a coming together, I believe, in this Congress of those of us in both political parties in recognizing that medical research is something that we all should be supporting.

But I think what I am hearing from you today is that even those of us who support medical research need to be more sensitized to where those research dollars are going, and that children, and this particular disease, may be shortchanged.

I would like for you to share with me how you feel about that conclusion, and if you think that is something that those of us in Congress should be sensitized to.

Ms. YOUNG. I just want to say when my son was diagnosed with autism, nobody knew anything. I had to kind of guess at treatment. We have no real specialists. I can't take my son, like, to a normal—like they would treat my 5-year-old girl. There are all these ideas out there, but there is no specific treatments. And let me tell you something, when you don't have a physician you can take them to that understands the disease, it is just like they have a texture and sensory thing. Like my son doesn't eat because he doesn't like the texture of something, and I tell my doctors, well, he will eat when he wants to, it is just real hard.

My son on Friday, Friday I had strep throat and I called my doctor and she said why don't you come in, we will check that you have it. My son never had a temperature. When I took him in, I went in and I took him with me, they looked in his throat and he was loaded with strep and he couldn't tell me. My son could have died from strep. Strep will kill you if it goes undiagnosed. It is not just a life-long disability; these children can also die by not being diagnosed because they can't tell you.

Mr. STRICKLAND. I think I am somewhat aware of the burden that you experience because being a psychologist, I am aware that early on autism was most often blamed on the interaction between the child and the mother, of the child and the parent, and we were so ignorant, and thankfully, at least in that sense, we are better informed than we were. But I want to thank you for sharing your pain with us, because people like you put a human face on these circumstances, and I think it makes all of us not only better informed, but better people as we interact with those of you who are willing to share your stories with us.

Thank you.

Mr. BILIRAKIS. Would the gentleman yield?

Mr. STRICKLAND. Yes, sir.

Mr. BILIRAKIS. The gentleman's time is up. The Chair will use his prerogative. There is no cure. How much benefit is there to realizing or diagnosing it early on?

Mr. SHESTACK. We say something, we say half of all people with autism will never learn to talk and will never live independently, but half of them very well might and maybe even more than that. And the absolute key factor of that is discovering that your child has autism as early as possible and getting into early intervention, which might mean speech therapy or occupational therapy.

It is not the new magic bullet, it is not today's latest cure. It is therapies we all know. But if you apply them very aggressively to children with autism, it can make a tremendous difference between a child who can speak and tell you when he has a tummy ache or a toothache, or a child who never can and grows increasingly frustrated.

So this aspect of early diagnosis is critical just for taking care of the people who we have now. Of course, the other thing that is important to know about this bill and the scientists we have spoken to today about this now say the research we fund today is going to be the treatments of tomorrow. And without that funding, we have nothing, and we are living the way we have lived for the past 50 years with this disease. These bills both really strongly address this and will teach pediatricians all around the country how to catch autism, because any one of us could walk into a preschool and spend 20 minutes and say that is the kid that has autism. We know how. When we see it, we know. But pediatricians need to be trained, and it is easy training to do.

Mr. BILIRAKIS. I am sorry.

Ms. RUSSO. Even in the schools, I know when my daughter was checked for scoliosis, it is very simple. That would be something else, that the bill would help to just educate people, teachers, parents, early education. My nanny's son really benefited from early intervention.

Ms. YOUNG. And my son is doing much better.

Mr. BILIRAKIS. That was the point I thought, with the media being here and Ms. Russo responsible for it for the most part, I think that is something, you know, we want to try to find a cause, we want to try to find a cure, do all of these things, but education and informing, which I don't know, and prevention obviously, but we don't know really what causes it.

Mr. SHESTACK. There are things we can do now if kids get caught early.

Ms. YOUNG. And there are a lot of States that don't help parents. I am lucky to live in New York and they help me with the ABA that my son gets, applied behavioral analysis. I talked to mothers all over the country, refinancing their homes, getting third mortgages, losing their homes because they need to get intensive therapy for their children.

Mr. BILIRAKIS. Mr. Greenwood.

Mr. GREENWOOD. This last point really needs to be stressed, because it hasn't been brought up in the hearing. The $6 million that goes for physician education is critical. Parent after parent has said to me, I took him to the pediatrician, I said there was something wrong with the kid, the pediatrician said wait, it will go away, it

didn't. We lost a year, 2 years, 3 years, before we had any kind of opportunity to do adaptive work with these children. We want the doctors to pick up on this right away and then get the kids the help that they need. It makes a lifetime of difference.

Mr. BILIRAKIS. Somebody used Alzheimer's as an example. You are right, just 15 or 20 years ago, they couldn't——

Ms. YOUNG. It was senile dementia.

Mr. BROWN. If I could ask for 60 seconds?

Mr. BILIRAKIS. Without objection.

Mr. BROWN. Thanks to all three of you. I appreciate Mr. Greenwood's comments. He is exactly right. It begs the question of the fact there are 45 million people in this country that have no health coverage, that this Congress seems not to address that. We should double the NIH budget, we should take care of the things that Mr. Strickland and Ms. DeGette and others have said we should, but even as we move toward a cure and move toward earlier intervention and diagnosis and all that we can do in that, if we don't cover the 40 million, in some sense at least you all now know what to do to makes things a tiny bit better, but so many don't have health care coverage don't. This Congress needs surely to move on that as inexorably, if you will, as we do on NIH funding.

Mr. BILIRAKIS. We can excuse this panel. John, it is important I think that you share with us what CAN is doing, the bank that we talked about, and any other things that you feel might be significant to share with us here, because it may sound like we know a lot about this disease and others, but we don't. So we need your help.

Ms. YOUNG. Thank you very much.

Ms. RUSSO. Thank you very much.

Mr. SHESTACK. Thank you very much.

Mr. BILIRAKIS. The second panel consists of Mr. Wes Mahr, accompanied by Ms. Mackenzie Mahr, on behalf of the Juvenile Diabetes Foundation International, please come forward; Mr. Bill Pierce, National Council for Adoption; Dr. Meyer Kattan, Department of Pediatrics, Mount Sinai Hospital; and Dr. Richard Weisman, Department of Pediatrics, University of Miami School of Medicine, on behalf of the American Association of Poison Control Centers.

Welcome. Your written statement is made a part of the record. I will turn the clock on 5 minutes and hopefully you can sort of compliment, if you will, or supplement your written statement. Thanks so much for your patience. We are running behind, but that is nothing new up here. We are very fortunate so far, we haven't been called for a vote. Possibly maybe we can finish up before that happens.

Mr. Mahr, you and Mackenzie kick it off for us. Take your time. Use the mike.

STATEMENTS OF WESLEY MAHR, ACCOMPANIED BY MACKENZIE MAHR, ON BEHALF OF JUVENILE DIABETES FOUNDATION INTERNATIONAL; WILLIAM PIERCE, NATIONAL COUNCIL FOR ADOPTION; MEYER KATTAN, DEPARTMENT OF PEDIATRICS, MT. SINAI HOSPITAL; AND RICHARD S. WEISMAN, DEPARTMENT OF PEDIATRICS, UNIVERSITY OF MIAMI SCHOOL OF MEDICINE, ON BEHALF OF AMERICAN ASSOCIATION OF POISON CONTROL CENTERS

Ms. MAHR. Hi. My name is Mackenzie Mahr. I am 7 years old, and I have had diabetes for 1½ years. I don't like having diabetes because I have to test my blood sugar at least four times a day and give myself insulin shots twice a day. The finger pricks make my fingers very sore and the shots bruise my body and hurt a lot. I have to watch everything I eat and get regular exercise to stay healthy, but even doing all the right things, I still sometimes have very high and very low blood sugars.

Sometimes I just feel sad and angry. Diabetes is not fun and I can't take a vacation from it. My diabetes is a 24-hour, 7 days a week, no-break disease. Diabetes is very scary because I don't know what the future holds for me. I feel that I am doing my part to help people understand what a bad disease diabetes is.

I spoke at two Juvenile Diabetes Foundation lunches to kick off the Baltimore area walks to cure diabetes. I filmed a TV commercial about diabetes, and my family and I raised over $3,000 for the JDF to find a cure for diabetes. This summer I participated in the JDF children's Congress in Washington, DC. There were nearly 100 kids like me from all 50 States who asked you for money for research and to help and to promise to remember all the children with diabetes. We need your help to find a cure for diabetes. I promise that I will take care of myself while I wait for a cure. I hope that you can do your part to help me and my friends.

Thank you.

Mr. BILIRAKIS. Thank you. Please proceed, lieutenant.

Mr. MAHR. Thank you, Mr. Chairman. It is my privilege to testify before you today and the committee. I would just like to pick up on a parent's perspective to add to what Mackenzie said. On March 9th, 1998, we received the devastating news that our child had been diagnosed with Type 1, or juvenile, diabetes. After a grueling 3-day crash course on how to care for a child with diabetes, we were sent home to begin our new life. Our new life with diabetes began officially that following Thursday morning when we had to give our daughter the first of many insulin shots. The process of just giving her one injection lasted over 90 minutes, with many tears and heartbreak.

The next 2 weeks left us emotionally distraught and physically drained. Our fears were never ending. Every night we put our daughter to bed we were worried she would suffer from low blood sugar and never wake up. A year and a half later our fears have not diminished.

Our days now are consumed by a strict routine. Mackenzie wakes at 7:30 a.m., she tests her blood sugar and gives herself an insulin injection. She then eats a breakfast that has been carefully adjusted to meet her body's needs. At 9:30 a.m. She eats a snack. At 11:30 a.m. She again tests her blood sugar and she eats lunch.

At 1:30 p.m., another snack. At 3:30 she arrives home from school, she tests her blood sugar and she has a snack. At 5:30 p.m. She tests her blood sugar and gives herself another insulin injection and again eats a meal that is appropriate for her blood sugar level. At 8:30 p.m. She tests her blood sugar, and she eats a snack, and it is bedtime. The next day she gets to do it all over again.

In addition to this, we will occasionally have to awake her in the middle of the night to test her blood sugar, just for peace of mind.

What I have just described is the best case scenario for a normal day. If Mackenzie is ill or has a day of activity, her whole insulin and testing schedule can be completely turned inside out. As parents, our entire day is focused, although not always successfully, on trying to maintain a normal blood glucose level for Mackenzie. Insulin, although it is a wonderful life sustaining drug, is not a cure. Low blood sugar can affect Mackenzie's ability to learn in school and can lead to seizures or unconsciousness.

As you are aware, high blood sugar can result in devastating consequences, including blindness, amputations, kidney failure, heart disease and stroke. Mackenzie's future will remain uncertain unless a cure is found.

As a congressional employee for almost 15 years, I have observed Congress firsthand tackle a national problem with great resolve. I simply ask that you do the same to help Mackenzie and the tens of millions of Americans who have diabetes or a loved one affected by the disease. Please provide the research funds necessary to support the Diabetes Research Working Group report that has identified hundreds of diabetes research opportunities that remain unfunded solely because of a lack of money. Also I ask that you add to any children's health legislation the specific juvenile diabetes initiative submitted to you by the Juvenile Diabetes Foundation.

With your leadership, Mr. Chairman, and the dedicated work of the Congressional Diabetes Caucus, co-chaired by Representative DeGette, I know that we will find a cure.

Thank you.

[The prepared statement of Mackenzie and Wesley Mahr follows:]

PREPARED STATEMENT OF MACKENZIE MAHR

Hi. My name is Mackenzie Mahr. I am 7 years old, and I have had diabetes for a year and a half. I don't like having diabetes. It has affected my whole life. I have to test my blood sugar at least four times a day and I give myself insulin shots twice a day. The finger pricks make my fingers very sore and the shots bruise my body and hurt a lot. I have to watch everything I eat and get regular exercise to stay healthy. But even doing all the right things, many times my blood sugars swing from very high to very low.

Sometimes I just feel sad and angry. Diabetes is not fun and I can't take a vacation from it. My diabetes is a 24 hour, 7 days a week, no-break disease. Diabetes is very scary and I don't know what the future will hold for me. I feel that I am doing my part to help people understand what a bad disease diabetes is.

I spoke at two Juvenile Diabetes Foundation lunches to kick off the Baltimore-area Walk to Cure Diabetes. I filmed a TV commercial about diabetes. And my family and I raised over $3000 at several JDF Walks this year to help find a cure for diabetes. I participated this summer in the JDF Children's Congress in Washington, DC. There were nearly one hundred kids with diabetes, like me, from all 50 states who asked you for money for research and to promise to remember all the children with diabetes. We need your help to find a cure for diabetes. I am doing the best I can to take care of myself while I wait for a cure. I hope that you all will now do your part.

Thank you.

PREPARED STATEMENT OF WESLEY MAHR ON BEHALF OF THE JUVENILE DIABETES FOUNDATION INTERNATIONAL

On March 9, 1998, we received the devastating news that our child had been diagnosed with Type 1, or juvenile, diabetes.

After a grueling three-day crash course on how to care for a child with diabetes, we were sent home to begin our new life. Our new life with diabetes began officially that Thursday morning when we had to give our daughter the first of many insulin shots. The process of just giving her one injection lasted over 90 minutes with many tears and heartbreak. The next two weeks left us emotionally distraught and physically drained. Our fears were never ending. Every night we'd put our daughter to sleep, we'd worry if she would suffer from low blood sugar and never wake up. A year and a half later our fears have not diminished.

Our days now are consumed by a strict routine:

7:30 AM: Mackenzie wakes and tests her blood sugar and injects her insulin. She then eats a breakfast that has been carefully adjusted to meet her body's needs.
9:30 AM: She eats a snack
11:30 AM: She again tests her blood sugar and eats lunch
1:30 PM: She eats another snack
3:30 PM: She tests her blood sugar and has a snack
5:30 PM: She tests her blood sugar and receives an insulin injection and again eats a meal that is appropriate to her blood sugar level.
8:30 PM: She tests her blood sugar, eats a snack, and goes to bed. The next day she gets to start all over again.
Middle of the night: We sometimes need to wake her up to test her blood sugar

What I have just described is the best case scenario for a normal day. If Mackenzie is ill or has a soccer game, her whole insulin and testing schedule can completely be turned inside out.

As parents our entire day is focused on trying, not always successfully, to maintain a normal blood glucose level for MacKenzie. Insulin itself is not a cure. Low blood sugar can affect MacKenzie's ability to learn in school and can lead to seizures or unconsciousness. High blood sugar can result in devastating consequences, including blindness, amputations, kidney failure, heart disease and stroke. Mackenzie's future will remain uncertain unless a cure is found.

As a Lieutenant in the Capitol Hill police and a member of the force for 15 years, I have observed first-hand Congress tackle a national problem with resolve. I simply ask that you do the same to help Mackenzie and the tens of millions of Americans who have diabetes or have a loved one affected by the disease. Please provide the research funds necessary to support the Diabetes Research Working Group report that identified hundreds of diabetes research opportunities nut funded solely because of lack of money. Also, I ask that you add to any children's health legislation the specific juvenile diabetes initiatives submitted to you by the JDF.

With your leadership, Mr. Chairman, and the dedicated work of the Congressional Diabetes Caucus, co-chaired by Rep. DeGette, I know that we will find a cure.

Thank you.

Mr. BILIRAKIS. Thank you very much, sir. I know that was so tough on you.

Mr. Pierce.

STATEMENT OF WILLIAM PIERCE

Mr. PIERCE. Chairman Bilirakis and members of the subcommittee, thank you for inviting the National Council for Adoption to present testimony today.

My name is Bill Pierce, and I am the president of the council.

The National Council for Adoption is a national not-for-profit organization founded in 1980 to promote and defend adoption and to work on behalf of a wide range of adoption-related issues. Of particular relevance to this hearing is our work with children with special needs, those children, especially those with developmental disabilities, who are most likely to end up in the public child welfare system and who are candidates for adoption from foster care.

It is the prevention aspect of this picture that I will be focusing on in my oral testimony. We believe that if the Congress takes

steps that result in the improvement of children's health, fewer children will enter the system.

We are also of the opinion that if Congress ensures that better counseling is provided to pregnant women who may be told that they are pregnant with a child likely to have developmental disabilities, that more of these women will be comfortable in either choosing to parent their challenged children, or will plan adoption for those children without the children ever needing to pass through the expensive and slow-moving foster care system.

I am here today to encourage the subcommittee to take steps that would have the following results: Provide better data about the incidence and types of disabilities characterizing children in out-of-home care in the public sector, especially in the public child welfare system. I might add parenthetically that the testimony that we have heard in our first panel about the lack of data about children that are affected with autism is the kind of epidemiological data that can be picked up by better reporting from the public foster care system as well.

We need reports on the extent to which counseling is provided to pregnant women who are encountered by professionals who could offer information and education about the realistic challenges that parents of children with disabilities face and the types of supportive services available to help those parents cope with these challenges, ranging from early prenatal education to prenatal tests, such as sophisticated imaging technologies, including ultrasound, to fetal surgery, to adoption planning for their children with special needs.

We also need to stimulate additional research into ways fetal surgery can produce better results for children diagnosed with conditions that may be ameliorated in utero.

The reasons for our concerns are several. HHS's web site reports that 110,000 children in the public foster care children have adoption as their goal. Of the percentage of children available for adoption, half have developmental disabilities. An unknown number of the children in out-of-home arrangements came into care directly or indirectly as a result of their developmental disabilities or health conditions. Some presented such challenges and the challenges are the kinds you have been hearing about today, that their biological parents could not cope and voluntarily relinquished them.

Others, perhaps the vast majority, were removed involuntarily from the custody of their biological parents because of neglect and abuse. Within that context it is not known what precise role substance abuse plays as opposed to the presenting problems of the parents themselves.

Whatever the complex of causes, the Nation faces a daunting human and fiscal crisis, whether one considers the total universe of more than half a million children in substitute care or the still enormous 110,000 children identified as needing adoptive families.

Early identification of children who may eventually enter the system by providing diagnosis and treatment to women with high risk pregnancies could reduce the numbers of children born with developmental disabilities and other health problems. Reducing those numbers should result in fewer children entering the system.

Combining early counseling for biological mothers, fathers and other kin with early services for children, should result in better planning for the children. More will be able to make informed choices about parenting, and those who are less likely to be successful parents will make adoption plans earlier and without the necessity of expending the time, resources and human suffering involved in most involuntarily terminations of parental rights.

It is far easier to find families for children who are younger and who have spent a shorter time in the foster care system, so introducing these measures should not only decrease the pool of children in care, but increase the percentage in care who find adoptive families. These changes, taken together, should have a substantial impact in reducing the numbers of children and ultimately adults who remain in long term or permanent care, funded at least in part by Federal programs.

We respectfully urge the subcommittee as it looks at ways to improve children's health and thereby build a better future, to provide more Federal involvement for funding of fetal research and surgery, to require HHS and other Federal agencies to provide more detailed data about disabilities of children in out-of-home care and the relationship of disabilities to termination of parental rights and adoption, to provide more supportive services to women with high risk pregnancies, including prenatal tests such as ultrasound and counseling aimed at increasing adoption awareness.

Thank you.

[The prepared statement of William Pierce follows:]

PREPARED STATEMENT OF WILLIAM PIERCE, PRESIDENT AND CEO, NATIONAL COUNCIL FOR ADOPTION

Chairman Bilirakis and other Members of the Subcommittee, thank you for inviting the National Council For Adoption, Inc., to present testimony today. My name is William Pierce and I am President and CEO of the National Council For Adoption.

The National Council For Adoption is a national, not-for-profit organization founded in 1980 to promote and defend adoption and to work on behalf of a wide range of adoption-related issues. We do not currently receive any federal grants or contracts, including subgrants or subcontracts.

Of particular relevance to this hearing is our work with children with special needs, those children—especially those with developmental disabilities—who are most likely to end up in the public child welfare system and who are candidates for adoption from foster care. Our organization spent two years conducting a foundation-funded study of foster care and published a comprehensive report listing some of the steps the federal and state governments could take to improve the situation through prevention and provision of services. Many of the suggestions made in that report were incorporated in the Adoption and Safe Families Act passed by the Congress and signed into law in 1997.

But much more needs to be done in respect to preventing children from entering foster care or moving children more quickly from foster care to permanent, adoptive families. And it is the prevention aspect of this picture that I will be focusing on in my testimony. We believe that if the Congress takes steps that result in the improvement of children's health, fewer children will enter the system. We also are of the opinion that if Congress ensures that better counseling is provided to pregnant women who may be told that they are pregnant with a child likely to have developmental disabilities that more of these women will be comfortable in either choosing to parent their challenged children or will plan adoption for those children without the children ever needing to pass through the expensive and often slow-moving foster care system.

We also believe that there is an excellent case example of the positive role that can be played by health care researchers, an example which should encourage the Congress to move forward assertively. That example is the research done at NIH on the use of AZT to reduce perinatal transmission of the HIV/AIDS virus to babies.

Part of that example also is the necessity to mount an aggressive campaign of public health education to overcome well-meaning resistance to a tested medical intervention. Our AIDS Orphan Adoption Project has played a modest role in advancing public policy in respect to children and adults living with HIV/AIDS.

We also are involved in many other activities, including: 1) operating the National Adoption Hotline and an International Adoption Information Clearinghouse; 2) promoting adoption for all children through legislation and media efforts such as those focusing on the elimination of race and ethnicity as a factor in placing children in foster care or adoption; 3) working to improve tax fairness and a full range of adoption benefits so that more families may be able to adopt; 4) encouraging ethical, sound and responsive adoption practices by all those who provide adoption service and maternity homes (we have both adoption agencies and adoption attorneys in our membership); 5) offering facts and guidance to the media so that adoption is accurately portrayed; 6) supporting privacy and the promises of confidentiality made to people involved in adoption; 7) protecting the security of children and others involved in adoption by filing friend-of-the-court briefs; 8) doing basic policy research; 9) conducting broad-based public education efforts through a publications and conference program.

I am here today to encourage the Subcommittee to take steps that would have the following results:

1) provide better data about the incidence and types of disabilities characterizing children in out-of-home care in the public sector, especially in the public child welfare system;
2) report on the extent to which counseling is provided to pregnant women who are encountered by professionals who could offer information and education about the realistic challenges parents of children with disabilities face and the types of supportive services available to help those parents cope with these challenges, ranging from early prenatal education to prenatal tests such as sophisticated imaging technologies including ultrasound, to fetal surgery to adoption planning for their children with special needs;
3) stimulate additional research into ways fetal surgery can produce better results for children diagnosed with conditions that may be ameliorated in utero.

In our view, these are some of the solutions to these problems.

First, our organization is keenly aware of the potential positive impact of medical interventions based on sound research. No more dramatic example comes to mind than the progress made in recent years in preventing transmission of HIV/AIDS from mother to child. If one refers to major types of developmental disabilities on the web site of the National Adoption Information Clearinghouse maintained by the U.S. Department of Health and Human Services (HHS), one finds seven different categories listed, including AIDS. In the National Council For Adoption's AIDS Orphan Adoption Project, we publicize the fact that a 1994 National Institutes of Health study found that giving the drug zidovudine (also called AZT) to an HIV-positive pregnant woman and to the baby at birth reduced by two-thirds the risk of transmission. Eight percent of the babies born to women who were treated became infected compared to 25 percent among babies born to untreated women. Dramatic improvements in the life span of adults living with HIV/AIDS have also been noted. The impact of these improvements has meant many fewer children orphaned by HIV/AIDS and ending up in the foster care system, the child welfare system or otherwise in need of assistance from the public human services systems. Similar, if less dramatic, improvements can be made for other categories of developmental disabilities, we believe.

The reasons for our concerns are several.

—HHS' web site reports that 110,000 children in the public foster care system have adoption as their goal. (NAIC, oddly, puts the number at less than half, 40-50,000.)
—NAIC estimates that of the percentage of children available for adoption, half have developmental disabilities.
—As of 1994, nearly 20 percent of the total children in out-of-home substitute care had one or more disabilities: the Voluntary Cooperative Information System (formerly administered by the American Public Human Services Association with funding from HHS) put the national estimate at 83,671 of 465,820 for Fiscal Year 1994, the last year for which data are available.
—An unknown number of the children in out-of-home arrangements came into care directly or indirectly as a result of their developmental disabilities or health conditions. Some presented such challenges that their biological parents could not cope and voluntarily relinquished them. Others, perhaps the vast majority, were removed involuntarily from the custody of their biological parents because of neglect or abuse. Within that context, it is not known what precise role sub-

stance abuse plays as opposed to the presenting problems of the parents themselves. Whatever the complex of causes, the Nation faces a daunting human and fiscal crisis whether one considers the total universe of more than half a million children in substitute care or the still-enormous 110,000 children identified as needing adoptive families.

—Early identification of children who may eventually enter the system by providing diagnosis and treatment to women with high-risk pregnancies could reduce the numbers of children born with developmental disabilities and other health problems. Reducing those numbers should result in fewer children entering the system.

—Combining early counseling for biological mothers, fathers and other kin with early services for children should result in better planning for the children: more will be able to make informed choices about parenting and those who are less likely to be successful parents will make adoption plans earlier and without the necessity of expending the time, resources and human suffering involved in most involuntary terminations of parental rights.

—It is far easier to find families for children who are younger and who have spent a shorter time in the foster care system, so introducing these measure should not only decrease the pool of children in care but increase the percentage in care who find adoptive families.

—These changes, taken together, should have a substantial impact in reducing the numbers of children—and ultimately adults—who remain in long-term or permanent care, funded at least in part by federal programs.

My area of expertise is not medicine, but I would like to just briefly summarize the highly encouraging progress made in fetal research and surgery as part of my call for more federal involvement in this area. Our view is that this involvement will lead to a more enhanced quality of life for children at risk while simultaneously reducing the ultimate net cost of caring for these individuals.

In 1973, according to the March of Dimes, the first successful in utero treatment took place. (By way of disclosure, I should mention that in 1960-61 I was employed by the March of Dimes as a State Representative and had Western Iowa as my responsibility.)

In 1989, the first case of congenital diaphragmatic hernia (CDH) was corrected prenatally. CDH is said to occur between 1 in 2,000 to 1 in 5,000 births. The mortality for fetuses and neonates diagnosed with CDH is high, ranging between 40—100 percent .

In the November 21, 1998 *Lancet* a team from Children's Hospital in Philadelphia reported their successful open fetal approach to spina bifida repair, which has now become the standard for this procedure. Presently, several dozen such surgeries have been performed by a team at Vanderbilt University Hospital. Spina bifida is said to occur in 1 of every 2,000 births.

Fetal surgery has also been successful in cases which are not life-threatening, such as amniotic band syndrome, as well as in more serious conditions, such as in correcting heart conditions.

At this point, let me speak about two specific examples relating to the health of children and how a different outcome might have resulted. In both instances, there was a recommendation for termination but counseling was provided so that alternatives such as parenting or adoption could be considered.

In the first instance, provided to me by Susan Dillon, a Milwaukee woman who, with her husband, is part of an ad hoc support group for parents of children with Down Syndrome. Mrs. Dillon works closely with Janet Marchese, the New York volunteer who heads A K.I.D.S. Exchange, an adoption exchange which specializes in counseling parents expecting children with Down Syndrome and which maintains a large waiting list of couples who wish to adopt children born with Down Syndrome. The case involved a married couple who were told, after amniocentesis, that the fetus had Down Syndrome.

The mother reports that she was told "this is going to ruin your marriage," "your family will be devastated," and "the grandparents and other relatives will not be supportive." The woman reports that she was counseled by a clinical nurse specialist, but the adoption option was never brought up. The only choices were "continue the pregnancy (with the assumption that parenting was expected)" or "termination." The woman reports that she and her husband were never told, "if you can't handle this, you don't have to choose termination." The woman and her husband ultimately chose to continue the pregnancy but she reports that the knowledge of the adoption option and the fact that there are dozens of qualified couples waiting to adopt "takes a lot of the pressure off." The woman reports "a lot of people panic, because in this situation, there is a very brief window during which one must make a decision." Mrs. Dillon reports that in Wisconsin, 70 percent of Down Syndrome

pregnancies are terminated. Mrs. Dillon also reports that, of the ten women in her support group, only three couples knew in advance that the baby would be born with Down Syndrome. The other seven found out at birth.

The point of this case is that if the experience of this small sample in Wisconsin is at all typical, a minority of pregnant women learn in advance of significant developmental disabilities, such as Down Syndrome. Of those who do learn about such a serious challenge, the option of adoption may not be mentioned, and the lack of choices may be a factor in the high percentage of terminations. Further, as the support group has come together, the parents have shared the fact that there is very little competent counseling for parents who give birth to children with Down Syndrome or other serious developmental disabilities.

If this is the case with a group of married, mature couples facing the challenge of a child born with serious health conditions, imagine what the response is of a young, unmarried woman who has little or no prenatal care or who is herself struggling with drug or alcohol addiction, joblessness and other problems. What is likely to be her response in the unlikely event that she learns, before birth, that her fetus is likely to be born with significant problems? Is adoption going to be discussed with her, as a potential option? And after giving birth, in the more likely scenario that the problems come as a complete surprise, what is her response? All too often, as the data show, these frightened and panicked young women abandon their babies at the hospital, setting the stage for years of "family preservation" or "family reunification" services and adoption only as a last resort five or six years later. Or, if the overwhelmed young single mother takes the developmentally disabled baby home and tries to parent, what are her chances of success given her limited resources? Is it any wonder that overwhelmed adolescent mothers of children with developmental disabilities are likely to neglect or abuse such children, and that these children later show up in the foster care system?

How much better it would have been to provide a means for these mothers, indeed all mothers, with an opportunity for ultrasound and other interventions as part of a program of prenatal care! How much more cost-effective it would be to provide truly competent counseling about all the options, including adoption, so that if a young mother is unable or unwilling to raise a challenging newborn, the entire foster care detour can be avoided and the baby can go to a waiting, prepared adoptive family.

Here is another case, in the Washington metropolitan area. This was the second pregnancy for a young married couple whose first pregnancy and delivery, in the Richmond, Virginia, area, had been uneventful. Early in the pregnancy, the woman developed symptoms that suggested a possible miscarriage and an ultrasound was suggested by her obstetrician. The ultrasound was not entirely clear, and a fetal echocardiogram was performed. The medical team then suggested a high-level ultrasound, which resulted in a diagnosis of multiple problems with the fetus" heart, a missing kidney, an abnormal umbilical cord and suggestions that the child could have any of a number of chromosomal abnormalities, specifically trisomy 13, 18 or 21. That same day, termination was suggested to the young couple.

The pregnant woman, a Chemical Engineer by training, happened to be a very sophisticated medical consumer. She had worked at NIH for two years and had considered studying to be a physician. The pregnant woman, in consultation with her husband, decided to carry the pregnancy to term and that if the child were born with a serious condition that meant she would live only a few days, they would make plans in advance to donate organs and tissue to other babies. As the young woman said, knowing the medical situation in advance, there was a medical team ready—at two hospitals—to deal with the problems that might be present at the baby's birth. The young mother reports "I can't imagine how difficult it would have been to deal with all this at birth, not having any preparation. As it was, knowing the information in advance, I had the ability to know about trisomy and kidney and heart difficulties and I was able to research. I did research on the internet and through calls and referrals. I contacted people in advance and got e-mail pen-pals who had children born with conditions similar to what the medical experts were telling my husband and me we might expect. One of my e-mail contacts was in Denmark, the other in North Carolina." As it turned out, the woman delivered a baby who experienced significant distress, was close to death, was placed on a ventilator, was later transferred to Children's Hospital and underwent additional intensive care. At one point, the medical team was suggesting that the baby would need to have a lung removed. But ultimately, the situation turned around, the baby was released and today she is "despite the negative early prognosis and neonatal difficulties—a healthy eight-month-old.

My point is that because of early and sophisticated medical intervention, these parents—and especially this mother—was prepared to deal with the medical situa-

tion of her child. Fortunately, she was able to be her own advocate and researcher. Not many women are so situated either by education, experience, opportunity or personality. For other mothers, someone else must be the researcher, the counselor, the person providing full information so that the options are all presented.

These are the kinds of predictable situations which, left without being adequately addressed, will have less than ideal outcomes for pregnant women, their families and the broader society.

In summary, we respectfully urge the Subcommittee, as it looks at ways to improve children's health and thereby build toward a better future, to:

—provide more federal involvement for funding of fetal research and surgery;
—require HHS and other federal agencies to provide more detailed data about disabilities of children in out-of-home care and the relationship of disabilities to termination of parental rights and adoption;
—provide more supportive services to women with high-risk pregnancies, including prenatal tests such as ultrasound, and counseling aimed at increasing adoption awareness.

Thank you again for inviting us to present testimony. It is important to mention that, because of the timing of this hearing, the testimony was not reviewed by or cleared with our Board of Directors and therefore does not necessarily reflect the views of all of our Board, member agencies, member attorneys, individual members, supporting foundations or corporations or other individual members, donors or volunteers.

I would be pleased to respond to any questions.

Mr. BILIRAKIS. Thank you Mr. Pierce. Is it Dr. Kattan?

Mr. KATTAN. Yes.

Mr. BILIRAKIS. Doctor, you are on, sir.

STATEMENT OF MEYER KATTAN

Mr. KATTAN. Thank you, Mr. Chairman, and members. I am Dr. Meyer Kattan, a professor of Pediatrics at Mount Sinai School of Medicine in New York City. Today I am testifying on behalf of the American Lung Association and its medical section, the American Thoracic Society, regarding asthma. I appreciate the invitation to testify and I want to thank Congressman Upton and Congressman Waxman for introducing the Childhood Asthma Relief Act. Much of what I will recommend today is contained in their legislation.

There are three key points that I would like to make in my testimony today. Point 1, asthma is a serious pediatric health problem in the United States; point two, though tools exist for children to successfully manage their asthma, we are not reaching all Nation's children and point three, the Federal Government needs to develop a plan to respond to our Nation's asthma epidemic.

Asthma is a serious pediatric health problem. Asthma is the most common chronic disease of childhood, affecting 5 million children under the age of 18 years in the United States. Prevalence for pediatric asthma rose 160 percent between 1980 and 1994. Rates are increasing for all ethnic groups, especially for African-Americans and Hispanic children.

Asthma is expensive. The growth of the prevalence of asthma will have significant impact on our Nation's health care expenditures, especially Medicaid. Currently asthma costs over $7 billion a year.

Children are disproportionately affected by asthma. Asthma is the No. 1 cause of school absenteeism. In 1995, there were over 1.9 million visits to the emergency room for asthma. In 1996, in New York City, there were more than 15,000 hospitalizations for asthma in children less than 14 years of age. This figure translates into one child being admitted to a New York City hospital every 35 min-

utes. Conditions of poverty and social disadvantage greatly influence the risk for hospitalization.

The hospitalization rate among children in East Harlem, which is where I work, is 23 times as high as the rate in the community with the lowest hospitalization rate in New York City. By any measure, and for any category, asthma is a growing problem for our Nation's children. The U.S. Health care system is not successfully responding to the asthma epidemic. What a public health tragedy that we have a disease that disrupts the lives of so many children despite the fact that we have the capability of allowing children to lead normal lives.

Obviously there are many barriers that prevent successful management of this disease. The drug regime is complex. Children with moderate to severe asthma need to be educated on how to use a number of drugs. Drugs need to be carefully coordinated with how the patients feel and with their daily monitoring. Getting the drug regimen right is not enough to successfully control asthma. The hope of a child of asthma needs to be free of asthma triggers. This can mean ridding a home of cockroaches, dust mites and tobacco smoke. Some children are being under-medicated, therefore changing patient and physician behavior must be an integral part of think asthma initiatives.

Asthmatics in inner cities have limited asthma problem solving skills and high levels of life stress. Attention to psychological and social factors that affect asthma are necessary to reduce morbidity and studies show that even with insurance, families in the inner city have difficulty getting access to good medical care for an asthma related episode or for a follow-up after an asthma attack.

Indoor and outdoor air pollution plays a role. Children, families, schools, coaches need to be made aware that air quality can cause asthma attacks, and while many of my comments today focus more on the size and complexity of the asthma problem, there is encouraging news to share with you. I work with the National Institute of Allergy and Infectious Disease on the Inner City Asthma Study. This project has shown that by empowering patients to effectively communicate with health care providers, providing social support and educating and assisting families in controlling exposures to indoor asthma triggers, we can achieve a reduction in asthma symptoms.

For the past 10 years, the NHLBI has sponsored the National Asthma Education and Prevention Program. This program focuses on providing clinicians and patients with the latest information on how best to manage asthma. The Health Resources and Services Administration supports pediatric pulmonary centers. These centers consist of interdisciplinary staff who train leaders in asthma care and assist State and local agencies in developing systems of care. Clearly the Federal Government needs to develop a public health response to asthma.

In my brief testimony I have listed at least four different Federal Cabinet level agencies that have a role in responding to asthma: The Department of Health and Human Services, the Department of Education, the Department of Housing and Urban Development, and the Environmental Protection Agency. Coordinating work in diverse Federal agencies on asthma will take planning. More specifi-

cally, we strongly recommend the creation of a Federal asthma plan.

In conclusion, I want to remind the committee that asthma is a serious public health problem. Our health system has tools to successfully control asthma, but many barriers exist to provide optimal disease management to all children. Last, we need a Federal asthma plan to help coordinate the many public and private activities in asthma.

Thank you, and I would be happy to answer any questions.

[The prepared statement of Meyer Kattan follows:]

PREPARED STATEMENT OF MEYER KATTAN, PROFESSOR OF PEDIATRICS, MOUNT SINAI SCHOOL OF MEDICINE

I am Dr. Meyer Kattan. I am a Professor of Pediatrics and Chief of the Pediatric Pulmonary and Critical Care Division at the Mount Sinai School of Medicine in New York City. Today, I am testifying on behalf of the American Lung Association and its medical section, the American Thoracic Society, regarding asthma. I appreciate the invitation to testify today and I want to thank Congressman Upton and Congressman Waxman for introducing the Childhood Asthma Relief Act. Much of what I will recommend today is contained in their legislation.

There are three key points I would like to make in my testimony today. Point one: asthma is a serious pediatric health problem in the U.S. Point two: Though tools exist for children to successfully manage their asthma, we are not successfully sharing the tools and information with all our of nation's children. Point three: The federal government needs to develop a plan to respond to our nation's asthma epidemic. I would like to spend the next few minutes expanding on these three points.

Before I do that, let me first tell you what asthma is. Asthma is a chronic lung disease in which the lungs are inflamed and more sensitive than normal. When the lungs are irritated, the bronchial tubes of the lungs become swollen and constrict, preventing air from getting into or out of the lung. These obstructive spasms of the bronchi are caused by a broad range of triggers that vary from one asthma sufferer to another.

Asthma is a serious pediatric health problem. Asthma is on the rise. Asthma is the most common chronic disease of childhood affecting 5.3 million children under the age of 18 years in the United States. The prevalence for pediatric asthma rose 160% between 1980 and 1994. Rates are increasing for all ethnic groups and especially for African American and Hispanic children. While some children appear to out grow their asthma when they reach adulthood, most, three-quarters will require life-long treatment and monitoring of their condition.

Asthma is expensive. The growth in the prevalence of asthma will have significant impact on our nation's health expenditures, especially Medicaid. Currently, asthma costs the U.S. over $7.5 billion a year.

Children are disproportionately affected by asthma. Asthma is the number one cause of school absenteeism. In 1995 asthma was the cause of over 1.9 million visits to the emergency room. Asthma is the reason for one-sixth the of all pediatric emergency room visits. In 1996 in New York City, there were more than 15,000 hospitalizations for asthma in children 14 years or younger. This figure translates into one child being admitted to a New York City hospital every 35 minutes. Conditions of poverty and social disadvantage greatly influence the risk for hospitalization. Children from low-income communities are five times more likely to be hospitalized as children in high-income communities. The hospitalization rate among children 0-14 years in East Harlem which is adjacent to Mount Sinai Hospital where I work is 23 times as high as the rate in the community with the lowest hospitalization rate in New York City.

By any measure and for any category, asthma is a growing problem for our nation's children.

The U.S. health care system is not successfully responding to the asthma epidemic. As a doctor who sees children with asthma, I am continually frustrated by needless suffering and expense that surrounds children with asthma. Much of the school absenteeism, the visits to the emergency room and the hospitalizations are preventable. Today, we have powerful drugs that can safely allow children manage their asthma. Through proper use of drugs to control the underlying chronic airway inflammation, rescue drugs to stop asthma attacks as they happen, careful patient and physician monitoring and through reduced exposure to asthma triggers, children with asthma can live healthy active lives. Despite the good news that asthma

is controllable, there are many barriers that prevent successful management of the disease.

The drug regime is complex. Children with moderate to severe asthma need to be educated on how to use a number of drugs. Which drugs to use and how much of each drug to use will vary on how the children are feeling. Drug use needs to be carefully coordinated with how the patients feel and what their daily peak flow reading says.

Asthma drugs can be expensive. For those families without insurance or with low prescription drug caps, purchasing asthma medications can be expensive. This is a particular problem for families on a tight budget.

Asthma drugs need to be accessible. Many schools have policy that prevents students to carry any type of prescription medication with them. In these schools, asthma inhalers end up locked up in the school nurse's office. Children, with parental permission, need to be able to carry the inhaler with them to school so they can immediately treat asthma attacks. Keeping asthma medication with the school nurse does not provide the immediate response necessary to prevent asthma attacks.

Multiple factors contribute to asthma morbidity and therefore treating asthma requires a variety of strategies. Getting the drug regime right is not enough to successfully control asthma. The home of a child with asthma also needs to be free of asthma triggers. This can mean ridding a home of cockroaches, dust mites, encouraging parents to stop smoking, removing carpeting, giving away the family dog, and making the house dust and mold free. This can be especially difficult in public housing. Families need help in identifying what are the triggers for their child's asthma attacks and removing those triggers from the home. Studies show that even with insurance, families in the inner-city have difficulty getting access to good medical care for an asthma-related episode or for follow-up after an asthmatic attack. Access to care needs to be facilitated. The pattern of medication use suggests an underutilization of preventive medications. Therefore changing physician and patient behavior must be an integral part of an asthma initiative. Asthmatics in inner-cities have limited asthma problem-solving skills, multiple caretakers, child and adult adjustment problems and high levels of life stress. Attention to psychosocial factors that affect asthma are necessary to reduce asthma morbidity.

Schools also need to be made safer for children with asthma. School staff needs to be educated on how to respond to asthma attacks. Schools can also help children reduce their exposure to environmental triggers in the school setting that cause asthma. Leadership from the Department of Education would help resolve some of the school-related issues.

Indoor and outdoor air pollution also plays a role. High outdoor levels of ozone and high indoor levels of nitrogen dioxide from unvented gas stoves exacerbate asthma symptoms. Children, families, schools, coaches need to be made aware the air quality can cause asthma attacks in children with asthma. Depending on the air quality, outdoor activity should be limited or eliminated to prevent asthma attacks. However, we should not be content to let poor air quality turn children with asthma into prisoners of their own homes. The EPA has begun to study the relationship between air quality and asthma. We as a nation must do more to improve the air quality.

While many of my comments today have focused on the size and complexity of the asthma problem, there is encouraging news to share with you. Public and private programs are successfully overcoming some of the barriers that I have mentioned and are providing children the tools the need to successfully manage their asthma. The National Institutes of Health is sponsoring several activities that are making a difference.

The American Lung Association has developed a program called Open Airways for Schools. The program informs students of the actions they must take to help prevent an asthma attack and empowers them to better manage their asthma with the assistance of parents, teachers, school nurses and physicians. This is accomplished through six 40-minute lessons, which are taught by trained volunteers. The interactive approach utilizes group discussion, stories, games, and role-play to promote children's active involvement in the learning process.

The original Open Airways program was tested with over 200 children, primarily of African American and Hispanic descent. After completing the program, not only were the children better able to manage their asthma but their parents reported that they, too, took more steps to help control their children's asthma.

I work with the National Institute of Allergy and Infectious Disease on the Inner City Asthma Study. This project has shown that by empowering patients to effectively communicate with health care providers, providing psychosocial support, and educating and assisting families in controlling exposures to indoor asthma triggers,

we can achieve a reduction in symptoms, hospitalizations and emergency department visits.

The National Heart, Lung and Blood Institute is also taking a leadership role in responding to asthma. For the past 10 years NHLBI has sponsored the National Asthma Education and Prevention Program. (NAEPP). NAEPP focuses on providing clinicians and patients with the latest information on how best to manage asthma. NAEPP has pioneered efforts to make asthma information materials available in many languages and has developed culturally appropriate education materials.

The Centers for Disease Control and Prevention also has an important role to play. The CDC collects data on national asthma treats. Much of what we know about the prevalence of asthma comes from CDC efforts. Additionally, CDC has developed a public-private asthma program called ZAP Asthma. This program sends community health workers into the homes of low-income families to aid the family in reducing exposure to the asthma triggers that cause asthma attacks.

The Health Resources and Services Administration supports Pediatric Pulmonary Centers. These Centers consist of interdisciplinary staff who train leaders in asthma care and assist state and local agencies in developing systems of care.

Clearly, the federal government needs to develop a public health response to asthma. In my brief testimony, I have listed at least four three different federal cabinet level agencies that have a role in responding to asthma—the Department of Health and Human Services, the Department of Education, the Department of Housing and Urban Development, and the Environmental Protection Agency. Clearly getting four large and diverse federal agencies to work in a coordinated fashion on asthma will take planning. More specifically, we strongly recommend the creation of a Federal Asthma Plan. The "Federal Asthma Plan" should bring together key federal agencies, medical professional societies, voluntary health organizations, employers and patients to develop a federal plan to coordinate the many elements of an effective public health response to asthma. Components of a federal plan should include research, surveillance, patient and provider education, community awareness, indoor and outdoor air quality, and access to health care providers and medication.

In conclusion, I want to remind the committee that asthma is a serious pediatric health problem. Our health system has tools to successfully control asthma, but many barriers exist to providing optimal disease management to all children. Lastly, we need a federal asthma plan to help coordinate the many public and private activities in asthma.

Thank you and I would be happy to answer any questions.

Mr. BILIRAKIS. Thank you, doctor. Thank you very much.

Dr. Weisman.

STATEMENT OF RICHARD S. WEISMAN

Mr. WEISMAN. Mr. Chairman and members of the subcommittee, my name is Dr. Richard S. Weisman. I am a member of the Board of Directors of the American Association of Poison Control Centers as well as an Associate Professor of Pediatrics at the University of Miami School of Medicine and the Director of the Florida Poison Control Center in Miami.

Poisoning is the third most common form of unintentional death in the United States. It accounts for 285,000 hospitalizations, 1 million days of acute hospital care, and 13,000 fatalities each year. The total direct costs associated with poisoning exceeds $3 billion annually. That is more than we spend on gunshot wounds, burns and drownings each year.

Poison centers are our Nation's primary defense against injury and death from poisoning. Twenty-four hours a day the general public and health care practitioners contact their local poison centers for help in diagnosing and treating victims of poisoning. With rapid diagnosis and treatment, both common and exotic poisonings, medical outcomes are improved and countless lives are saved.

In 1998, our Nation's poison control centers answered more than 2 million poisoning emergency calls, more than 1 million of these

cases involved children under the age of 6. In over 70 percent of these poisonings, the patient was managed safely at home.

Since a call to the poison control center is much less expensive than a trip to the emergency department, the result is a dramatic cost savings for the health care system and taxpayers.

In a recent study sponsored by the Department of Health and Human Services and published in the Peer Review Journal, the Annals of Emergency Medicine, poison centers reduced medical spending by up to $400 million annually. The cost savings from poison centers could even be greater if more people knew how to call them.

Currently there are over 130 different telephone numbers for poison centers instead of one standard nationally recognized and easily remembered telephone number. Today if you dial the number of a poison center that does not operates in your area, you will hear "you have reached a nonworking number from your area code." To the parent of a 2-year-old who has just swallowed someone else's prescription medicine, this can be devastating, but poison centers have not had the money to implement an integrated telephone network.

Despite their successes, poison centers struggle to exist. Most centers are funded by a fragile patchwork of State, local and private dollars.

Mr. Chairman, you and your colleagues have a wonderful opportunity to help poison centers to prevent poisonings and improve survival. We are extremely grateful for the efforts of Congressman Fred Upton and Congressman Edolphus Towns, who have introduced House bill 1221, and to Chairman Bilirakis for his leadership and to the 12 committee members that have signed on as cosponsors.

The Poison Control Center Enhancement and Awareness Act of 1999 will stabilize poison control centers. It will further reduce the cost of health care.

It will allow poison control centers to develop and improve poison prevention and it will improve care of the victims of poisoning. We hope that in the upcoming days you will support the anecdote for our Nation's poison control centers.

Thank you very much.

[The prepared statement of Richard S. Weisman follows:]

PREPARED STATEMENT OF RICHARD S. WEISMAN, CHAIRMAN, GOVERNMENT AFFAIRS COMMITTEE, AMERICAN ASSOCIATION OF POISON CONTROL CENTERS

Mr. Chairman and Members of the Subcommittee: My name is Dr. Richard S. Weisman. I am a member of the Board of Directors of the American Association of Poison Control Centers, as well as an Associate Professor of Pediatrics at the University of Miami School of Medicine and the Director of the Florida Poison Information Center in Miami. Prior to accepting that position I was the Director of the New York City Poison Center for more than a decade.

Poisoning is the third most common form of unintentional death in the United States. At least one out of every 75 U.S. citizens will be exposed to a potentially toxic substance every year. More than half of these exposures will involve children under the age of 6 who are exposed to poisons in their own homes. Poisoning accounts for 285,000 hospitalizations, 1.2 million days of acute hospital care, and 13,000 fatalities yearly. The total direct costs associated with poisoning exceed $3 billion annually. That is more than we spend on gunshot wounds, burns or drownings yearly.

Poison centers are our nation's primary defense against injury and death from poisoning. Twenty-four hours a day, the general public and health care practitioners contact their local poison centers for help in diagnosing and treating victims of poisoning. These poisonings involve everything from aspirin and household products to snake bites, insecticides, major chemical spills, and workplace chemicals. Poison centers are now working with the Centers for Disease Control and Prevention to develop responses to toxic weapons of mass destruction. With rapid diagnosis and treatment of both common and exotic poisonings, medical outcomes are improved and countless lives are saved.

In 1998, our nation's poison centers answered more than two million poison emergency calls. Most often, these calls were from a mom, a dad, or a child care provider. In Florida alone we receive over 500 calls from frantic parents each day. With poison center assistance, 70% of these poisonings can be managed safely at home. Since a call to the poison center is much less expensive than a trip to the emergency department, this results in dramatic cost savings to health care systems and taxpayers. A 1995 study, sponsored by the Department of Health and Human Services and published in the peer-reviewed journal *Annals of Emergency Medicine,* showed that poison centers reduced medical spending by up to $400 million annually. But the cost savings from poison centers would be even greater if more people knew how to call them.

Currently, there are over 130 different telephone numbers for poison centers instead of one standard, nationally recognized, and easily remembered telephone number. Today, if you dial the number for a poison center that does not operate in your area, you will hear: "You have reached a non-working number from your area code." To the parent of a 2-year old who has just swallowed someone else's prescription medicine, this can be devastating—but poison centers have not had the money to implement an integrated phone network.

In fact, despite their success, poison centers struggle to exist. Most centers are funded by a fragile patchwork of state, local, and private monies. Since poison centers do not generate revenue, they have been easy targets when sponsoring hospitals and state legislatures trim their budgets. The result is more catastrophic than such well-intentioned administrators can imagine. The cost of poisoning increases dramatically. There are fewer highly-trained toxicology experts to provide immediate treatment advice. The medical community loses a training environment. Parent education programs, which help prevent unintentional poisonings in the first place, are reduced or eliminated. In short, while the public loses a poison prevention program, a child's chance of surviving a poisoning is reduced.

Mr. Chairman, you and your colleagues have an opportunity to help prevent poisonings and improve survival from poisoning. Congressmen Fred Upton and Edolphus Towns have introduced H.R. 1221, the Poison Control Center Enhancement and Awareness Act of 1999. This bill will stabilize poison center funding, simplify access to poison centers, further reduce health care costs, and facilitate national poison prevention efforts. We support this effort. Your Senate colleagues, who passed the companion bill, S. 632, by unanimous consent, support this effort. On behalf of our country's children, we hope that you will, too.

Mr. BILIRAKIS. Thank you very much, doctor. Doctor Kattan, in your testimony you point out that although the barriers to managing asthma are significant, there are some public and private programs that are successfully overcoming some of these barriers. You note that at least four different Cabinet level agencies, HHS, HUD, the Department of Education and EPA, have a role in responding to asthma.

You recommend, and you mentioned it a number of times, a Federal asthma plan, that would bring together key Federal agencies, professional medical societies and volunteer health organizations to coordinate a range of activities designed to better manage asthma. Frankly, it seems so logical to me that I guess that is probably the reason why it hasn't been done up to now, because it makes so much sense.

You do feel that is a problem. You do feel that there is just lack of coordination. What, is there duplication of effort, things of that nature?

Mr. KATTAN. It is not simply a duplication of effort. I think there is a role for all of these agencies to coordinate these efforts. The problem is asthma is not a single disease. Many things have to be tailored to the particular problems. There is not one asthma fix. What is good in one community may not be the best in another community. What needs to be done, there are various programs that are available and have been shown to be successful. There are areas where our knowledge is lacking. We need better surveillance to know what the needs are.

If we know what is going on in each community and we can tailor our approaches that are available, we will succeed in controlling this disease. Remember, our goal is that children with asthma should be leading normal active lives.

Mr. BILIRAKIS. Are you aware of any existing models where the coordinations you referred to have been attempted and which have shown some success?

Mr. KATTAN. There is coordination in terms—at various levels. There is coordination in terms of having multi-disciplinary teams, which include social work, physicians, nurses, community workers, where one can integrate various programs.

Mr. BILIRAKIS. In areas other than asthma too? Not just asthma, not other than, but in addition to asthma.

Mr. KATTAN. In addition to asthma?

Mr. BILIRAKIS. Yes, successful coordination efforts.

Mr. KATTAN. I can't think of any off the top of my head, but I think there are examples where volunteer agencies have worked together with government, for example, the American Lung Association and the Cystic Fibrosis Foundation have worked together, in terms of directing research, in terms of providing community programs. I think those are good examples, and they have coupled with pharmaceutical companies as well.

Mr. BILIRAKIS. I would ask you, and maybe you threw in the American Lung Association, whatever, if you might furnish us with any information you may have where there are other efforts, where there are efforts in place for this coordination. Frankly, it makes a lot of sense to me. I even talked to staff about it.

Mr. KATTAN. Yes. I think for example, the National Institute of Environmental Health is working with the National Institute of Allergy and Infectious Disease in funding some research and the EPA. All three agencies are working together on the Inner City Asthma Study. There is an example where agencies can work to save money and get information and provide a program.

Mr. BILIRAKIS. Okay. I again am going to ask you not to respond now, but maybe you might think about it, and you seem to feel very strongly about it. That being the case, why don't you furnish us with details in terms of suggestions on how you think this ought to operate and work and what not so it can help us in terms of our deliberations.

Dr. Weisman, Mr. Brown can speak for himself, but he was sort of taken aback by some of the statistics you gave us, and that is one thing about this job up here, we learn about so many of these horrible things, horrible illnesses and what not and it just drives you up a tree that you can't waive a magic wand. You wish you could waive a magic wand to solve them all.

You are a proponent of poison control centers, and you don't feel that they should be—you believe very strongly in them and you feel that they should remain in place, if not expanded, is that correct?

Mr. WEISMAN. That is correct, sir.

Mr. BILIRAKIS. All right. You have also talked about a national 24 hour, I don't know if you said it in so many words, but you talked about one national line that would be available for people to call, rather than the montage of so many.

Mr. WEISMAN. That is correct. The situation that exists right now in the United States is that the average poison control center is receiving about 8 calls per 1,000 population. In areas of the country where they have knocked down the barriers of communication, that number goes up as high as 19 calls per 1,000 population.

One of the large problems that we face in the United States is this montage of 130 different telephone numbers, where it is very, very difficult for us to set up a partnership with industry who would be more than happy to assist with the advertisement of these numbers. If we had one single number in the United States, it would allow us to advertise on a nationwide basis and we would be able to reduce the number of unnecessary emergency department visits for poisoning.

Mr. BILIRAKIS. Thank you. I know Dr. Shiebler of the University of Florida, one of your rival universities, I guess in more than just football, is a strong proponent of that type of legislation.

My time is up. I wanted to recognize Mackenzie, who is such a gutsy, courageous little girl. In spite of the fact that you don't feel well, you are tough enough to be here. I will tell you something. Dad is a policeman in the District of Columbia, and he is a pretty tough guy. You have to be a pretty tough guy. So he feels very strongly about you and about your illness, honey, and that is why he broke down here.

We certainly appreciate all that. Thank you. Mr. Brown.

Mr. BROWN. Mr. Chairman, thank you. Mackenzie, I saw you touch your dad's hand and how much you love your dad and how much he loves you.

Mr. Pierce, thank you for your testimony about adoption. Dr. Weisman, as the chairman said, I was pretty amazed by some of the alarming statistics you mentioned and just that there is no toll-free number. You mentioned that there is no sort of—not toll-free, but national number for people to call. You said when you have knocked down the barriers of communication, you said that in response to his communication, the number went from 8 to 19. What does that mean, knock down the barriers of communication? What have you done in those communities?

Mr. WEISMAN. The State of Washington is the example I used where they have developed a wonderful poison prevention program. It is integrated into all of the education programs in school. Over a number of years of being able to increase their recognition and to bolster the capabilities of that center, they basically get all of the calls involving poisoning, where very few of those cases pick up the phone and dial 911 and rush off to the emergency room, only to arrive there and find they have a nontoxic exposure. That is where the vast majority of the dollar savings occurs, is the cost of a call to the poison center is $19, whereas the cost of that ride to the

emergency room and that emergency visit can be anywhere between $600 and $900 depending on the region of the country you are in. Seventy percent of all the calls the poison centers gets can be treated at home by the doctors and nurses in the poison center. Seventy percent. We believe that we can knock down that difference between 7 calls per 1,000, which is the average in the United States, and 19, which the State of Washington has been able to demonstrate is what you can get to, with the appropriate availability and access to a poison center. We think going to a single nationwide number would allow us to increase the number of calls dramatically as it begins to be advertised on products, as it begins to be advertised on network television and so forth.

Mr. BROWN. So no companies can put anything on a product because there is no uniform number. You mentioned 7 per 1,000. Is that per year?

Mr. WEISMAN. 7 per thousand per year.

Mr. BROWN. Thank you for that. That is very helpful.

Dr. Kattan, you mentioned in your discussion of asthma that the increase from 1980 to 1994 is 160 percent. When EPA Director Carol Browner came in and discussed the particular matter on the ozone issues a couple of years ago, there was a great deal of discussion about asthma, obviously.

In light of progress or lack of progress in clean air, what is the effect on asthma? Can you ascribe much of the air quality issue to the increase in asthma, and role that in, if you would, to minority populations who have been victimized, if you will, by a significantly higher increase?

Mr. KATTAN. I think we have to first distinguish indoor air quality and outdoor air quality, and I think we should be concerned about both issues. Indoor environment is very important, talking about exposure to cigarette smoke. We are talking about exposure to nitrogen dioxide, which comes predominantly from gas stoves, and that has been shown to increase symptoms. In areas where the houses are in disrepair, some of these gas stoves are not vented properly. We are living in homes which are more tightly sealed, so there is greater exposure to those indoor pollutants, plus the allergens in the home as well.

In terms of outdoor air pollution, air quality in some areas has improved, not in all areas, but asthma prevalence continues to go up. But there is no question that air pollution or poor quality air contributes to asthma symptoms and increases asthma symptoms. Ozone has been shown to increase asthma symptoms and increase emergency room visits. The diesel particles, they have been shown to be associated with increased respiratory symptoms as well.

More research needs to be done in terms of the relationship between air pollution and asthma, and also between whether air pollution actually increases the prevalence of asthma, not just increasing the symptoms. I think we have to distinguish between what brings on asthma and what exacerbates symptoms once you have asthma.

Mr. BROWN. But clearly the statistics show the incidence of asthma is higher. But you are not—science is not willing to ascribe air quality for sure to the increased incidence. They are certainly ascribing air quality as a component of bringing on more frequent

symptoms for those that have asthma, or extended symptoms, if you will.

Mr. KATTAN. That is correct.

Mr. BROWN. For extended symptoms, if you will.

Mr. KATTAN. There is some evidence that actual exposure to certain pollutants increases the response to certain allergens also provoking asthma.

Mr. BROWN. If I could, Mr. Chairman, to what do you attribute the increase in incidents? If it is——

Mr. KATTAN. We don't know. There are many things. In terms of the onset of asthma, certainly we know that maternal smoking during pregnancy and early in life increases asthma symptoms. Exposure to allergens. Maybe children are spending more time indoors in more tightly sealed homes playing with computers. Onset of asthma. Asthma, not symptoms.

Mr. BROWN. So you know for sure that pregnant women smoking is a cause and you believe indoor air quality is a cause.

Mr. KATTAN. Indoor exposure to dust mites. The more you are exposed to dust mites in the home or longer time and higher levels, the more likely you are to develop asthma. This is all recent evidence that certain aspects can affect the onset of asthma. More research needs to be done in this area. These are very long-term studies that need to be done before we have definitive answers.

Mr. BROWN. Thank you, Dr. Kattan.

Mr. BILIRAKIS. Ms. DeGette.

Ms. DEGETTE. Thank you, Mr. Chairman. Thanks for coming, Mackenzie. What grade are you in?

Ms. MACKENZIE MAHR. Second grade.

Ms. DEGETTE. Did I hear your dad say that you actually do your own injections?

Ms. MACKENZIE MAHR. Yes.

Ms. DEGETTE. How long have you been doing that?

Ms. MACKENZIE MAHR. I have done it since a few months.

Ms. DEGETTE. That is really great. I bet your mom and dad are really proud of you, and I bet your doctor is, too. I have a little girl, Frannie, and she is almost 6. She has Type 1 diabetes like you do. She has to sometimes pat her mom and dad on the hand, too, because it is hard for the moms and dads, too. I just want to tell you, we are really working hard in Congress so that we can cure this disease by the time you go to college. Don't you think that would be a good thing? We are going to work to do that and I think that you can help me. Maybe you would like to meet Francesca, my daughter, sometime. I think you guys would get along. Your dad and I will set up a play date, okay? Thanks. Thanks for coming.

Dr. Kattan, something you talked about struck me. I wonder if you know how many, on average, how many attacks do kids with asthma have per year? Do you have a sense of that?

Mr. KATTAN. It depends on what you mean by attack, but I won't evade the question. Let's talk about emergency room visits in an inner city population. An individual, which is a higher risk population, somewhere around two emergency room visits a year. But some children have over 10 and some children have none. The point is that it is a variable disease. Some of the programs would

be more effective if we targeted what population or what specific group we wanted to treat.

Ms. DEGETTE. Of that inner city population that you are talking about, do you know what percentage have private health insurance or Medicaid or some kind of health insurance?

Mr. KATTAN. I don't know the answer to that, but I know that in the inner city asthma study where we recruited patients randomly from emergency rooms, over 90 percent had insurance. I made the point that despite having insurance, there were still barriers to the care.

Ms. DEGETTE. What were those barriers?

Mr. KATTAN. Unable to reach doctors when their child was sick. Telephones that don't get answered in clinics or clinics that aren't open at night when the parents need help. So the choice is to go to the emergency room. Others, the barriers, parents felt that their doctors didn't know that much about asthma and preferred to go to the emergency room where they felt that the doctors had more experience.

Ms. DEGETTE. Are there pediatric asthma specialists that people can go to?

Mr. KATTAN. Yes, there are. There are pediatric pulmonologists, pediatric allergists, and there are some people in primary care who have an interest in asthma. But in major—and people who deal with a lot of patients with asthma, they also have the other personnel that are needed to deal with the psychological barriers, the social barriers that are important. These factors are very important in causing morbidity.

Ms. DEGETTE. Do you think that—of the population you saw, how many of them were seeing these pediatric specialists?

Mr. KATTAN. Not the majority. The majority were being taken care of in local health clinics.

Ms. DEGETTE. You said that seeing these specialists and the others that work with them assist in morbidity issues and other issues. Can it help decrease the number of emergency room visits, do you know statistically?

Mr. KATTAN. Yes. There have been studies to show patients taken care of by people who specialize in asthma, that there is an improvement in outcome. I want to point out that one of the interventions that we did in the inner city asthma study, we used an innovative approach. We did not use doctors. We used an asthma counselor. The asthma counselor who was trained to deal with the specific issues of inner city children, whether it be social issues or access to air care issues or improving communication with the doctor, telling them what questions to ask and telling them what symptoms to tell the doctor, we found a significant reduction in symptoms. So there could be innovative ways to—given the limitations that we have. We can't have a specialist on every corner, but we can certainly extend our efforts.

Ms. DEGETTE. Were those people covered by insurance?

Mr. KATTAN. Yes, they were, most of them.

Ms. DEGETTE. Thank you. So it is a matter of getting them in the right places.

Mr. KATTAN. Yes.

Ms. DEGETTE. Thank you, Mr. Chairman.

Mr. BILIRAKIS. Mr. Strickland.

Mr. STRICKLAND. Thank you, Mr. Chairman. I was struck by the fact that, Dr. Kattan, you talked about these factors correlated with asthma, dust, and cockroaches and so on. And over the weekend I was in my district at the Osteopathic School of Medicine in Athens, Ohio, and was told that they had recently done some research in my rural Appalachian area where they found much higher incidents of asthma and diabetes and so on. And then I hear the discussion about the inner city children. It seems to me that the commonality between the Appalachian children that I represent and the inner city children is a matter of poverty and the fact that many of them live in environments and under conditions where it is difficult for some of these factors that you have mentioned to be eliminated. And so I am interested in your opinion about the correlation, the causal correlation between poverty and some of these problems that you have observed.

Mr. KATTAN. As I mentioned, obviously poverty is a major risk factor for asthma. But I think it deals with a lot of the problems, access to care, access to medication, access to good medical care, life stresses, social problems. There are priorities. If you don't have heat, you may let your child wheeze a little longer to the extent that you will only take him to the emergency room when there is—when the child is really having difficulty breathing and that is your only choice, to go to the emergency room. If you have a whole number of children running around cold, that is more important.

Mr. STRICKLAND. If you are burning wood or coal in a stove to keep warm——

Mr. KATTAN. Those are other indoor pollutants. The emissions from gas stoves, some people are using their gas stoves for heat. What we found in the inner city asthma study is that in the winter months the exposure to nitrogen dioxide was high and related to symptoms.

Mr. STRICKLAND. Something else that I thought of as you were talking, so many areas in my district are exposed to flooding conditions, people living in flood plain areas and they get flooded. Their houses get wet and the insulation gets wet and the mobile home gets wet and they try to let it dry out, and continue to live there. I assume those kinds of conditions would be very problematic for an asthmatic child as well.

Mr. KATTAN. Yes. What you are pointing out is there are many factors. One has to look at the factors in a particular area in a particular community. There is some commonality, but in terms of dampness and wet, mold is a major allergen in asthma. A lot of children are allergic to molds whether in inner cities, whether in Arizona, but all over the country. That and cockroaches, pet allergens, all of these are important.

Mr. STRICKLAND. So the answer is not only good specialty medical care and proper medications and education, but also living environments and that is——

Mr. KATTAN. It is changing the environment, but I believe that tailoring programs to deal with individual—community issues or individual issues is what it takes. It doesn't mean that there needs to be a whole regimen for each individual patient, but there are methods at least identifying the risks and dealing with those risks.

Mr. STRICKLAND. I was also struck by Dr. Weisman's statistics regarding the number of deaths that occur with poisonings. What was the total number?

Mr. WEISMAN. 13,000.

Mr. STRICKLAND. I was wondering, Dr. Kattan, do you have an estimate as to the number of children's deaths that occur in our country each year because of asthma?

Mr. KATTAN. Yes. I believe it is under 1,000. Death is not—is a tragedy because it is a preventable disease. To have anybody die of asthma is devastating. But the real impact on day-to-day life is the day's loss of work for parents, day's loss from school, the great disruption of life that these children have because they have symptoms that go untreated. As I keep saying for the third time, a child with asthma should be normal. Anything short of that is a failure of our system.

Mr. STRICKLAND. I want to thank each of you. I would also like to thank Mackenzie. I think her father has obviously been a good father. We were all struck by how she was comforting you and for which you have to be thankful, sir. I thank you all very much.

Thank you, Mr. Chairman.

Mr. BILIRAKIS. Thank you, Mr. Strickland. Mr. Towns, to inquire.

Mr. TOWNS. Thank you, Mr. Chairman. Let me thank you for holding this hearing. I think this is a very important hearing and I am hoping that out of this the committee can come up with a comprehensive child health bill. In order to do that, I think that we have to look at all of the aspects. I know that this committee does not have jurisdiction over it, but there is another aspect that we need to look at very seriously, Mr. Chairman, and that is the toy guns.

As a result of toy guns—I know that this committee does not have jurisdiction over it, but the point is that when we look at this matter in a comprehensive way, I think we have to look at all of this. Even in my own district, I have had youngsters to be killed because of a toy gun and cause others to be injured because of toy guns. These guns look like real guns.

When I brought it into the airport, my aid, the people at the counter ducked behind the counter because they thought it was a real gun. Then they say that in order to show it is a toy gun, they put a red sticker on it. Now, the criminals are now painting the tips of their guns red, so that is not working. So we now have to come to grips with the fact that we must do something with this problem.

Of course, you have now the criminals are taking toy guns and robbing because in New York State, if you rob with a toy gun, you don't violate the Sullivan law. Which means lesser charges, therefore rob with a toy gun and if you get caught, you don't have to worry about the Sullivan law. At the same time kids are being killed. Police officers are not going to interview anybody if they have a toy gun. They are not going to say is your gun real or is your gun a toy. They are not going to ask those kinds of questions. They are going to shoot. As a result, many youngsters die as a result of this.

Mr. Chairman, in this country, every day, 27 kids, a whole classroom of kids are killed from guns. A whole classroom is wiped out

every day in the United States of America. We are sitting here not doing anything about it. When we look at comprehensive health care, we cannot ignore what is happening with our children with handguns. Look at that board there. Some of those guns look so real. There is no need for that. We should address that along with all of these other issues.

Let me move to thank you, Dr. Weisman, in particular for your efforts in poison control. The doctors are asking that we have a central number. They are saying that in the training that many times they don't know what to do when a mother shows up in the emergency room with a child. They need to have somebody to call that has had some training in this area. I think that the thing that really bothers me, Doctor, is that we are saving money by funding the poison control centers and we refuse to do it with any kind of consistency. So therefore a lot of people that have the knowledge walk away from the centers because they don't know whether or not they are going to have a job next month or not. That is not a way to deal with something as serious as this.

I want to applaud you for all of the work that you have done in this area, and to say to you that I am hoping as we move forward with this comprehensive bill that we will be able to have a set amount for poison control centers. I don't think that we should leave it where if we have some members up here in Congress who feel good on a given day will say that therefore we should give some money to poison control centers because we are talking about lives and we are talking about humans. That is the thing that we need to deal with.

Let me go to my quick question before the clock runs out on me. I think that, Mr. Chairman, that is, I think that when we look at the poison control centers, with everyone being so cost conscious in health care, I would like to know, Dr. Weisman, if you could comment on the health care savings achieved by people utilizing poison control centers versus the emergency rooms.

Mr. WEISMAN. The data that we have from this actually resulted from a congressional hearing that you chaired back in 1994, and we were very, very thankful because it has been your efforts that have really spearheaded our efforts in Congress this year and in the past. What that study which was conducted by HHS found was that for every dollar invested in poison control centers, that $7 could be saved. That is about the calls that we received in poison centers, and we get a lot of them. We could possibly get a lot more. The vast majority of them can be managed in the home by the parents under the supervision of the nurses and doctors in the poison center. They don't require the person to call 911 and run off to the emergency room and keep the doctors there busy, first, trying to find out what the product is and trying to find out how to treat it.

If that call goes to the poison center and the doctor in the poison center is saying, well, we need to store the products a little better but we are okay this time because one of those tablets is not going to hurt little Johnny, we just saved an awful lot of money. We know that 70 percent of all of the calls to a poison center can be managed just like that without any further cost to the health care system. What we need to do is to make it that every American citizen has access to a poison center, knows the number, knows that

when there is a poisoning they pick up the phone and dial the special 800 number. It doesn't cost them anything, they are immediately connected to a center with trained individuals, and this prevents the expense of using unnecessary health care resources. That is where the savings are.

We believe that with the particular bill that has been introduced with its $26.6 million that it has the potential of saving a tremendous amount of money because if we are able to move that margin from 7 calls per thousand up to 19 calls per thousand, the difference between those 2 are the people that are going unnecessarily to emergency departments. And I think that there is an awful lot of money that investment in this program will result in the future.

Thanks.

Mr. TOWNS. Thank you. Let me thank you, too, Mackenzie for coming and sharing with us. It means a lot. Who knows, as a result of you being here, maybe we will do the right thing. Thank you so much.

Mr. BILIRAKIS. You know, Dr. Weisman, in the exchange that you had with Mr. Towns talking about the savings for every dollar spent, $7 savings and whatnot, if only we could get the Congressional Budget Office to score this legislation accordingly and take that into consideration. But they don't. They charge us for that one dollar, but they won't give us the benefit of the $7 or benefit of anything. They won't give us the benefit of the 70 cents or 50 cents or $2 or whatever. That is really much of the problem we have up here. I suppose they are doing their job as they are chartered to do it, but that is so frustrating.

Preventive health care, for instance, and all of these things that you know darn well are going to save money ultimately, but you can't get any credit for it. That is part of the world that we live in.

Well, Mackenzie, and Lieutenant Mahr, Mr. Pierce, Dr. Kattan, Dr. Weisman, thank you again for being so patient. Thank you for being here. You have been a tremendous help. We have a tough job here because something new pops up all the time. We just have to do the best that we can. Without you we couldn't even address some of these problems.

Dr. Kattan, you owe us some information regarding your national or your Federal asthma plan. We may have and ordinarily do have questions for the rest of you that we would submit to you in writing and we would hope that you would in a reasonable period of time respond to them. Thank you very much.

Yes, Mr. Towns. Don't wave that gun around. Why don't you——

Mr. TOWNS. Mr. Chairman, I really hope that this committee, that every member would join me in trying to address the handgun situation in this Nation. The toy guns, I think that when we look at health care, you cannot ignore the fact that a lot of youngsters end up shot, end up in the emergency rooms, end up in the hospital beds as a result of walking around with a toy gun. I think when we talk about saving, economizing, talking about our health care system, we need to look at the total situation. I am hoping that your comprehensive bill will also include——

Mr. BILIRAKIS. I am not sure whether or not that is within our jurisdiction. I will tell you I have a daughter-in-law who will not

allow a toy gun in the house. But again, the jurisdictions are part of the—do a 1-minute. That he might do, a 1-minute.

Have you done a 1-minute on that subject?

Mr. TOWNS. I am going to do a 5-minutes, an hour, anything else I can do, Mr. Chairman, because I am committed to this. I have seen youngsters lose their lives as a result of the handguns.

Mr. BILIRAKIS. Thanks again so much. This hearing is adjourned.

[Whereupon, at 5:53 p.m., the subcommittee was adjourned.]

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